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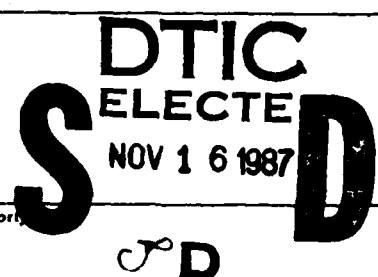
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PERCEIVED LIFE CHANGES IN ADULTS WITH ACQUIRED
IMMUNODEFICIENCY SYNDROME (AIDS) AND KAPOSI'S SARCOMA
UTILIZING A BEHAVIORAL SYSTEMS MODEL

ABSTRACT

✓ The lack of documentation regarding the true impact of an AIDS diagnosis leaves care providers, especially nurses, guessing at appropriate patient management. The objectives of this study were §1) to describe perceived life changes occurring in adult AIDS patients with Kaposi's Sarcoma in terms of occurrence, direction, quality, and importance, from a nursing perspective; §2) to evaluate the Derdiarian Behavioral System Model (DBSM) Instrument for validity, comprehensiveness, and reliability in an AIDS population.

Using a descriptive design, a convenience sample of 30 outpatients, with AIDS and Kaposi's Sarcoma, were interviewed. Data analysis included frequency studies, internal consistency analysis, a limited test-retest Pearson product-moment correlation, and a judge panel. Results provided measurable dimensions of perceived life changes in terms of occurrence, direction, quality, and importance. The DBSM Instrument proved valid (100%) and comprehensive (>97% by two judge panels). Internal consistency, measured by Cronbach's alpha, found a reliability of $\alpha = .84$ for direction, $\alpha = .94$ for quality, and $\alpha = .92$ for importance. The limited Pearson product-moment correlation found

medians of $r=.93$ ($p=.01$) for direction, $r=.89$ ($p=.01$) for quality, and $r=.87$ ($p=.02$) for importance.

Major areas of perceived change included dermatological manifestations, sexual expression, ability/desire to achieve, and emotional stability. The findings hold major implications for future nursing practice, education, and research. The empirical support found for the DBSM Instrument advocates: 1) the Johnson Behavioral Systems Model as a comprehensive framework for nursing practice; 2) the DBSM Instrument as a reliable, comprehensive, tool to guide both practice and research.

Los Angeles

Deborah Ann Schobel



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Perceived Life Changes in Adults with
Acquired Immunodeficiency Syndrome and Kaposi's Sarcoma
Utilizing a Behavioral Systems Model

by

Deborah Ann Schobel, Major, USAF NC

1987

A thesis submitted in partial satisfaction of the
requirements for the degree Master of Nursing

(221 Pages)

UNIVERSITY OF CALIFORNIA

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REPORT ON THE MASTER'S THESIS

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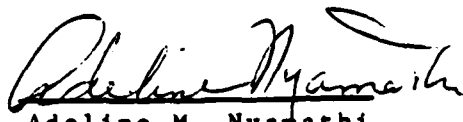
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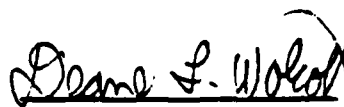
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Signature, Chairman of Committee

The thesis of Deborah Ann Schobel is approved.


Adeline M. Nyamathi


Deanne L. Wolcott


Anayis K. Derdarian, Committee Chair

University of California, Los Angeles

1987

This thesis is dedicated to the thousands of people living with a diagnosis of AIDS and to their nurses, who are trying to provide quality care for them and their loved ones.

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LIST OF ABBREVIATIONS/TERMS

AIDS	Acquired Immunodeficiency Syndrome
APLA	AIDS Project, Los Angeles
CDC	Centers for Disease Control
CNS	Central Nervous System
CNS	Clinical Nurse Specialist
DBSM	Derdiarian Behavioral System Model (Instrument)
GI	Gastrointestinal
GU	Genitourinary
HIV	Human Immunodeficiency Virus
I/D	Increase/Decrease
IMP	Importance
JBSM	Johnson Behavioral System Model
KS	Kaposi's Sarcoma
OCNS	Oncology Clinical Nurse Specialist
P/N	Positive/Negative
PHS	Public Health Service
Sample	Portion of Population Studied
UCLA	University of California, Los Angeles

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ABSTRACT OF THE THESIS

Perceived Life Changes in Adults with
Acquired Immunodeficiency Syndrome and Kaposi's Sarcoma
Utilizing a Behavioral Systems Model

by

Deborah Ann Schobel

Master of Nursing

University of California, Los Angeles, 1987

Professor Anayis K. Derdarian, Chair

A lack of documentation regarding the impact of a diagnosis of AIDS leaves care providers, especially nurses, lacking in guidance when trying to provide comprehensive care to these patients. The objectives of this study were (1) to describe perceived life changes occurring in adult AIDS patients with Kaposi's Sarcoma in terms of occurrence, direction, quality, and importance, from a nursing perspective; (2) to evaluate the Derdarian Behavioral System Model (DBSM) Instrument for validity, comprehensiveness, and reliability in an adult AIDS population.

Using a descriptive design, a convenience sample of

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30 adult outpatients with AIDS and Kaposi's Sarcoma was identified at the University of California, Los Angeles. The data was analyzed by frequency studies, internal consistency analysis, a limited test-retest Pearson product-moment correlation, and a judge panel to review added items. The data retrieved provided measurable dimensions of the perceived life changes (since diagnosis) in terms of occurrence, direction, quality, and importance. The DBSM Instrument was found to be valid (100%), and comprehensive (>97% by two judge panels). Internal consistency, as measured by Cronbach's alpha, found a reliability of $\alpha = .84$ for direction, $\alpha = .94$ for quality, and $\alpha = .92$ for importance. Additionally, the limited use of the Pearson product-moment correlation found medians of: $r = .93$ ($p = .01$) for direction, $r = .89$ ($p = .01$) for quality, and $r = .87$ ($p = .02$) for importance.

Major areas of perceived change included dermatological manifestations, sexual expression, ability/desire to achieve, and emotional stability. The resulting data base holds major implications for future nursing practice, education, and research. The empirical support found for the DBSM Instrument advocates: 1) the Johnson Behavioral Systems Model as a comprehensive framework for nursing practice; 2) the DBSM Instrument as a reliable, comprehensive, tool to guide both practice and research.

CHAPTER 1

INTRODUCTION

Nurses all over this country are finding themselves responsible for the care and management of patients with Acquired Immunodeficiency Syndrome (AIDS). As of March, 16, 1987, 32,365 individuals had been diagnosed with AIDS in the United States, including occurrences in every state (Center for Disease Control [CDC], 1987). Morgan & Curran (1986) estimate that by 1991 this country will be caring for over 144,000 AIDS patients. The Human Immunodeficiency Virus (HIV), known to cause this illness, appears to be spreading through our population at an alarming rate. An estimated 1 to 1.5 million individuals in this country are currently infected with HIV (Public Health Service [PHS], 1986). This promises the health care system a continuing plethora of AIDS patients beyond the year 1991 unless major medical breakthroughs occur that would allow us not only to prevent, but to reverse the activity of this virus.

Until such medical strides are achieved, nurses and other health care providers continue trying to identify ways of providing safe, comprehensive care for these patients. Currently, minimal information exists to guide the nurse in providing this type of care. The majority of published information addresses the issues of infection

control and virus transmission. Although this information is critical to nursing practice, it is not the only knowledge required for a nurse to provide comprehensive and quality care.

Fear and distrust continue to flourish when ever this most serious public health problem is addressed. The debilitating and fatal course of this illness, the sociocultural implications related to its transmission, and its initial appearance in certain socially stigmatized groups, have all contributed to society's great difficulty in dealing with it (Holland & Tross, 1985). The fear and suspicion of AIDS patients has not stopped at the entrances of our health care institutions. Murray (1985) addressed the moral responsibilities of health professionals in "Ethical Issues in AIDS". Unfortunately, despite the argument of "professional responsibility", fear and, in many cases ignorance, continues to affect the health care available to these patients. Dr. Sonnabend, involved in the treatment of AIDS patients in New York City stated: "All down the line there are frightened people. There are doctors and nurses refusing to treat sick people" (Weiss, 1983, p. 123). The only way to combat the fear, ignorance, and other problems inherent in providing comprehensive nursing care to these patients, is to provide nurses with the information they need to professionally deal with the

problem.

Research is flourishing in the area of HIV transmission and possible vaccines or curative treatments. Although information regarding communicability and potential cures is critical, nurses require much more information before they can meet the immediate nursing needs of AIDS patients. As evidenced by the literature review that follows, very little has been written regarding the experience of being an AIDS patient and thus, little resulting literature on effective nursing interventions for their many problems. What type of life changes do adult AIDS patients experience and how can these changes be identified in terms of nursing practice?

Nurses cannot provide comprehensive care without having an understanding of the perceived needs of the patients they care for. To provide a knowledge base from which one can develop effective nursing interventions for these patients, a descriptive study of adult AIDS patients, focusing on their perceived life changes is needed. The purpose of this study is to describe perceived life changes occurring in adult AIDS patients, manifesting Kaposi's Sarcoma, from a nursing perspective, utilizing the Derdarian Behavioral Systems Model Instrument. Stated as a hypothesis:

The Derdarian Behavioral Systems Model

Instrument, administered to a group of adult patients diagnosed with Acquired Immunodeficiency Syndrome (AIDS) manifesting Kaposi's Sarcoma, will reflect life changes (in terms of 8 subsystems) perceived by these patients. In so doing, it will provide a descriptive knowledge base that should lead to development of effective nursing interventions.

Specific objectives of this study include:

1). To describe perceived life changes occurring in adult AIDS patients with Kaposi's Sarcoma in terms of:

- a). Occurrence
- b). Direction (increase/decrease)
- c). Quality (positive/negative)
- d). Importance (scale of 0-100)

2). To evaluate the Derdiarian Behavioral Systems Model Instrument in the adult AIDS patient population for:

- a). Validity and Reliability
- b). Comprehensiveness

CHAPTER 2

THEORETICAL FRAMEWORK

Since the days of Florence Nightingale, nurses have struggled to focus their training and care on the patient, as a person, rather than on a specific illness. Meeting the needs of the "total patient" has become a standard of nursing care, especially in the last few decades. Recognition of this important characteristic of nursing led Dorothy E. Johnson to develop a philosophy of nursing (1959) and eventually a model which could be used by all nurses to more successfully achieve this goal (Fawcett, 1985; Johnson, 1968).

Because this study intends to emphasize a "nursing model", an explanation of the source of that perspective is addressed here. The nursing goals and focus of this study are consistent with those described within the Johnson Behavioral Systems Model (JBSM). Johnson (1968) maintained that nurses "conceive the patient as a behavioral system, in much the same way that the patient is conceived as a biological system in medicine". Additionally, she identified the goal of nursing to be "behavioral system equilibrium and dynamic stability" (p. 3). A further clarification of the Johnson nursing perspective is stated by Judy Grubbs (1980): Her [Johnson's] goals are the patient's comfort, the appropriate use of his energy to

adapt to the illness, and the maintenance of his developmental level of functioning (p.218-9).

The JBSM was founded on the conception that man is a behavioral system (Johnson, 1980). The model was based on Rapoport's definition that "A system is a whole that functions as a whole by virtue of the interdependence of its parts" (1968, p. xvii). Rapoport utilized Chin's (1961) work in building on the assumption that within a system:

(1) There is organization, interaction, interdependency and integration of the parts and elements.

(2) The system tends to achieve a balance among the various forces operating within it.

Johnson further assumed that this balance within the behavioral system was critical to the successful development and functioning of man. She theorized that most individuals probably experience, at one or more times during their lives, a psychological crisis or physical illness grave enough to disturb the system balance to a degree necessitating external assistance (Johnson, 1980). The purpose of her model lies within her belief that "Nursing is (or could be) the force that supplies assistance both at the time of occurrence and at other times to prevent such occurrences" (Johnson, 1980, p. 209).

The JBSM directs the nurses attention to eight distinct, yet open and interactive, subsystems within man.

Each has a specialized task or function needed to maintain the integrity of the whole behavioral system and its relationship to the environment (Fawcett, 1985). Grubbs' (1980) interpretation of the eight subsystems follows:

(1) **Achievement Subsystem**---to master or control oneself or one's environment; to achieve mastery and control.

(2) **Affiliative Subsystem**---to relate or belong to something or someone other than oneself; to achieve intimacy and inclusion.

(3) **Aggressive/Protective Subsystem**---to protect self or others from real or imagined threatening objects, persons, or ideas; to achieve self-protection and self-assertion.

(4) **Dependency Subsystem**---to maintain environmental resources needed for obtaining help, assistance, attention, permission, reassurance, and security; to gain trust and reliance.

(5) **Eliminative Subsystem**---to expel biologic waste; to externalize the internal biologic environment.

(6) **Ingestive Subsystem**---to take in needed resources from the environment to maintain the integrity of the organism or to achieve a state of pleasure; to internalize the external environment.

(7) **Restorative Subsystem**---to relieve fatigue and/or achieve a state of equilibrium by re-establishing or replenishing the energy distribution among the other

subsystems; to redistribute energy.

(8) **Sexual Subsystem**---to procreate, to gratify or attract, to fulfill expectations associated with one's sex; to care for others and be cared about by them. (Grubbs, 1980, pp. 226-228).

Johnson (1968) proposed that these subsystems may be subject to disequilibrium as a result of illness. Although the human behavioral system has the inherent ability to adapt to change, instability results when stressors exceed the individuals coping abilities (Grubbs, 1980).

This behavioral system considers the social and cultural factors involved in human responses, as well as the biological and psychological (Fawcett, 1985; Johnson, 1980). With nursing defined as the "diagnosis and treatment of human responses to actual or potential health problems" (American Nurses' Association, 1980) it would appear that this model provides the nurse with a more comprehensive picture of the patient's needs.

The JBSM has proven to be a successful model for nursing practice when applied to several types of patients. Damus (1980) applied the JBSM to post-transfusion hepatitis patients. Her results "unequivocally support the utility and practicality of applying the Johnson behavioral model in nursing practice" (p.289). In 1983 Derdiarian's research supported the theory that the cancer patient

manifests behavioral changes in each of the JBSM subsystems. Derdiarian went on to develop an instrument to describe and document patient behavioral changes based on the JBSM. Identified as the Derdiarian Behavioral System Model (DBSM) Instrument, this instrument was found both valid and reliable (Derdiarian & Forsythe, 1983). She concluded that the "JBSM provides a comprehensive conceptual framework on which patient behavior may be described and measured" (p.266).

In 1968, Johnson called for nursing research to focus on the task of identifying and describing the behavioral system disorders which arise in connection with illness, and to develop the rationale for and the means of management (Johnson, 1968). As a result of her own research with cancer patients, Derdiarian concluded: "The design of the DBSM Instrument provides a system to describe and document patient behavioral changes as to the existence, direction, quality, and importance of those changes, and the illness effects associated. This (instrument) forms a rational basis for patient or nursing problem definition and nursing intervention" (Derdiarian & Forsythe, 1983, p. 266).

AIDS patients are complex patients with a multitude of needs: Physiological, psychological, sociological, etc. In view of the need for an accurate picture of these patients from a nursing perspective, an application of this

instrument (based on the Johnson Behavioral Systems Model/Theory) appears to be a natural research pathway.

CHAPTER 3

REVIEW OF THE LITERATURE

A diagnosis of AIDS brings with it a myriad of physical, psychological, and social problems. It is considered a catastrophic event because of its rapid downhill course, lack of definitive treatment, and extremely poor prognosis (Holland & Tross, 1985). Although the focus of this study is identifying and documenting the patient's perception of life changes secondary to an AIDS diagnosis, it is important to identify the general forces that this patient may be responding to.

Medically speaking, virtually every biological system may be affected by this illness (Gong, 1985). Central to an actual diagnosis of AIDS is identification of a "disease that is at least moderately indicative of an underlying cellular immune deficiency" without other known causes for possible immunosuppression (Dale & Avers, 1986). This basic immune deficiency is persistent and is the major feature of AIDS (Groopman, 1983). It results in a patient's susceptibility to a wide range of opportunistic infections including a variety of protozoa, fungi, viruses, and mycobacteria (Gong, 1985; Selwyn, 1986c). Even non-opportunistic infections such as tuberculosis, and bacterial pneumonias are increased in these patients (CDC, 1986a; Selwyn, 1986c). Besides the assault of infectious

agents, AIDS patients are very susceptible to certain malignancies, especially Kaposi's Sarcoma and non-Hodgkin's lymphoma (Dale & Avers, 1986; Selwyn, 1986c). As a result of these multiple types and varieties of infections and malignancies, and their subsequent treatment attempts, these patients may deal with major problems in every organ system: Pulmonary, gastrointestinal, dermatological, ophthalmologic, neurologic, hematological, and renal impact is common; cardiac and endocrine impact also may occur. (Gong, 1985; Selwyn, 1986).

The psychological status of these patients is impacted by both the neurological impairments and the psychosocial sequela associated with this disease. Neurological impairments include infections of the nervous system by HIV and other opportunistic invaders of the nervous system (Wolcott, Fawzy, & Pasnau, 1985). The most common dysfunction of the nervous system is a nonfocal encephalopathy, with dementia as a dominant symptom (Holland & Tross, 1985). Levy, Bredesen, & Rosenblum (1985) reported that at University of California, San Francisco, 80% of autopsied AIDS patients had nervous system pathology.

In addition to these neurological impairments, these patients must deal with a multitude of psychosocial problems. Most must cope with a terminal disease at a relatively young age. Eighty nine percent of those diag-

nosed with AIDS are between 20 and 49 years of age (Dale & Avers, 1986). Utilizing Erickson's stages of ego development, one notes that the developmental tasks of that age group focus on 1) intimacy (mutuality with a loved partner) and 2) generativity (producing) (Malasanos, Barkauskas, Moss, & Stoltenberg-Allen, 1977). Loss of one's job, strength, social role, mental acuity, and independence are psychologically devastating (Holland & Tross, 1985). The social impact of this disease is integrated with the psychological impact as the patient responds to rejection from family, friends, and society in general. Besides precipitating fears of contagion, many times the diagnosis has forced the revelation of previously hidden drug usage or varied sexual practices to family, friends, and coworkers (Selwyn, 1986d). Risk of transmission to past, as well as future sexual partners, and perinatal transmission (Dale & Avers, 1986) serve to further feelings of guilt and withdrawal from others.

These extensive biological, psychological, and social problems result in a patient population that requires an enormous amount of attention from the health care system. Selwyn (1986d) noted that the resulting care of AIDS patients is extremely time consuming and labor intensive. Furthermore, he stresses that "sustained support from concerned and sensitive health professionals is critical to

help patients and families negotiate the many challenges posed by the disease" (p. 125).

Assuming, for a moment, that the nursing population is both concerned and sensitive to AIDS patients, how do they go about meeting the many needs that must exist? Especially considering the fact that a majority of AIDS patients currently come from a social/cultural background that is quite different from that of the average registered nurse in this country. Dale & Avers (1986) note that 73% of AIDS patients are homosexual or bisexual men and 17% are intravenous drug abusers. A review of resources guiding the concerned, sensitive nurse towards specific problems and appropriate nursing interventions becomes essential.

Patients with AIDS are seriously ill and eventually terminally ill. They have a tremendous need for sophisticated medical and nursing care. Although an increasing amount of literature is addressing the medical diagnosis and treatment of the various manifestations of AIDS, virtually no research is available addressing the nursing needs of these patients. Many articles have addressed the infection control concerns but they provide minimal information about how to meet the many nursing needs of this patient population. Their focus has been one of getting the nurse in and out of the room safely rather than on what

she needs to do once she gets in there (Batton & Tabor, 1983; Viele, Dodd, & Morrison, 1984).

A few exceptions to this include Ryan's (1984) article discussing AIDS as a threat to both physical and psychological integrity. This author explains the nurse's role of assessment, diagnosis, and intervention with this patient population. This brief article could not provide a comprehensive or detailed review, nor was it research based. However, it did stress attempts to "understand individual responses to AIDS" and focused on the psychosocial aspects of a nursing assessment utilized at National Institute of Health. A second publication that provided nurses with an excellent reference for understanding the disease and identifying specific nursing interventions etc. for AIDS patients actually was written as a self-care manual (Lang, Spiegel, & Strigle, 1985). Although this is an invaluable reference, it does not address individual assessment/needs from a nursing perspective. Additionally, it is not research based but rather a collection of ideas and advice from a team of professionals. More recently, publications attempting to fill that void of needed information have appeared. Coleman (1986) did address the needs of an AIDS patient from a nursing perspective but there was no framework given for her assessment and as a result, it was far from comprehensive. It, like several other ar-

ticles that followed (Royal College of Nursing, 1986; Schietinger, 1986), was based on general experiences rather than research based conclusions. There is definitely a lack of research based literature addressing the needs of AIDS patients from a nursing perspective.

Given the framework discussed in the previous chapter, one could draw from the literature to speculate on what one might expect to see as perceived life changes experienced by AIDS patients. A literature review supports the proposal that the AIDS patient experiences changes in each of the dimensions identified in the Derdiarian Behavioral Systems Model (DBSM) Instrument. The dimensions of the model are derived from the subsystems within the Johnson Behavioral Systems Model (Derdiarian, 1983). Let us examine the dimensions of each subsystem, in view of currently available literature and findings:

Achievement Subsystem: The goal is mastery of self and environment and the drive is the gratification of the ego (Johnson, 1968, 1980). The major extrapolated dimensions were "goal", "ability", and "importance" which resulted in the two categories: (1) physical and mental ability to achieve and (2) importance of achieving (Derdiarian, 1983). Christ & Wiener (1985), and Ware, (1985) report an overwhelming degree of physical and psychological impairment resulting from the disease

processes. Both noted that such impairment results in decreased ability to function in normal activities secondary to prolonged debility, profound fatigue and often, an incapacitating dementia. Approximately 2/3 of individuals dying from AIDS have significant brain abnormalities at autopsy (Wolcott, et al., 1985). A UCLA study of 42 AIDS patients (Wellish, 1984), found that the high level of fatigue had drastically impaired vocational functioning in many cases. Therefore, alterations in "ability" to achieve are expected.

Dale & Avers (1986) reports the age distribution of AIDS patients as follows: 22% aged 20-29, 47% aged 30-39, and 22% aged 40-49; all of which can be associated with young adulthood. The developmental tasks of young adulthood include choosing an occupation, establishing a career, forming enduring intimate relationships, and solidifying one's sense of identity (Christ and Wiener, 1985). It should, therefore not be surprising that in a support group study by Newmark (1984), fear of losing job, income, and becoming impoverished was listed as one of six primary issues confronting AIDS patients. One particular AIDS patient who was becoming extremely debilitated refused help with his activities of daily living as these actions represented the only evidence of mastering his illness that he could achieve (Lehman and Russell, 1985). It is thus

expected that the dimension of "importance" would be significantly impacted.

AFFILIATIVE SUBSYSTEM: The goal is the engagement in interpersonal relationships for the pleasure of interaction, and the drive is the need to belong (Johnson, 1968, 1980). The major dimensions identified were "other(s)" and "need" and "degree of association" (Derdarian, 1983). These dimensions were developed into three categories: (1) familial relationships, (2) relationships with friends and relatives, and (3) group relationships (Derdarian 1983). AIDS patients experience significant changes in all three types of relationships. AIDS patients claimed a lack of familial support and loss of harmony with family/lovers (Rubinou, 1984). Fear of contagion causes some family members to withdraw (Forstein, 1984) or patients to set up a self-imposed exile (Newmark, 1984). Exposure of the patients' homosexuality (72%) or drug usage (17%) secondary to the diagnosis may precipitate a crisis with family members (Christ & Wiener, 1985; Malyon & Pinka, 1983).

Discrimination by friends, relatives, employers, and even health care workers was a source of primary concern in Newmark's (1984) review of an AIDS support group. Forstein (1984) noted that the diagnosis of AIDS is so identified with socially undesirable groups, that essen-

tially all AIDS patients are stigmatized. Namir (1986) noted that these patients are often dealing with social avoidance for several reasons: social deviation (drugs, homosexuality), fear of contagion, and having a terminal illness. The loss of peer groups as a primary support is deeply felt by many AIDS patients as noted by Rubinou (1984) and Forstein (1984). Infection control measures frequently required with AIDS patients further suppresses affiliative activities (Wolcott, et al., 1985). Christ and Wiener (1985) found that the isolation was especially stressful for AIDS patients because it reminded them of previous experiences of discrimination and alienation. It is therefore apparent that AIDS patients undergo a significant amount of change in their affiliative relationships with "family", "friends and relatives", and "groups".

AGGRESSIVE/PROTECTIVE SUBSYSTEM: The goal is the protection of self and significant others and the drive is the need for protection (Johnson, 1968, 1980). Derdiarian (1983) identified the extrapolated dimensions to be "ability" and "need for protection" which were reflected in the categories of (1) physical ability, (2) emotional ability, and (3) cognitive ability. Physically, AIDS patients deal with an almost endless list of assaults. There is currently no known cure for the primary problem: a damaged or absent immune system (Gong, 1985; Wolcott, et

al., 1985). Almost all AIDS patients ultimately die secondary to an opportunistic infection (Reichert, O'Leary, Levins, Simrell, and Macher, 1983). AIDS patients live with the constant fear that their next infection may be their last, feeling extremely vulnerable and unprotected (Christ & Wiener, 1985; Lehman & Russell, 1985). Additionally, as noted by Christ & Wiener (1985), virtually all of these patients "waste away", experiencing profound fatigue and lethargy. Ophthalmological findings occur in over 50% of patients (Freeman, et al., 1983) with substantial loss of vision or complete loss of vision resulting (Kovacs & Masur, 1985). Other major symptoms of this disease noted in Lang, Spiegel & Strigle's (1985) guide to living with AIDS include pneumonia, thrush, weight loss, diarrhea, and fevers. The patients' physical compromises extend directly to their ability to provide financial security as they often cannot work, they are often lacking medical insurance and are soon devoid of any savings (Christ & Wiener, 1985). Obviously, these patients have a severe loss of physical ability to protect themselves, or others.

Emotionally, AIDS patients are faced with some overwhelming issues. The fear of dying, the fear of pain, disability, and disfigurement, the fear of infection, and the fear of becoming impoverished are four of the six

primary issues confronting AIDS patients (Newmark, 1984). Anger and depression are common (Furstenberg & Olsen, 1984). Perry & Tross (1984) noted that although there is a lack of hard data, the incidence of suicidal crisis, suicide attempts, and completed suicide appears to be quite high for AIDS patients.

Additionally, AIDS patients face a third type of assault in that their cognitive abilities are frequently affected by CNS infection, malignancy or other abnormalities. Perry & Tross (1984) found that 65% of hospitalized AIDS patients had evidence of an organic mental disorder. Cuff (1985) noted that changes in behavior and mental ability can become so severe that patients could no longer maintain personal hygiene or react properly to prevent injury. Newmark (1984) identified that AIDS patients are concerned that their ability to think and reason might be lost. Obviously, the categories annotating emotional and cognitive abilities are both very pertinent in AIDS patients.

DEPENDENCY BEHAVIORS: The goal is obtaining nurturance and the drive is the need for succor (Johnson, 1968, 1980). The extrapolated dimensions identified by Derdiarian (1983) were "need", "others", "dependence", and "functionality". The categories derived were (1) physical and (2) psychological/emotional dependency (Derdiarian, 1983a). Lehman & Russell (1985) noted that patients in

later stages of AIDS need assistance with everyday activities as the physical and psychological limitations are often profound. Christ & Wiener (1985) noted that in a study of 42 AIDS patients at Sloan-Kettering, 73% of the patients lived alone and that only 37% had friends or neighbors that would help them. Physical dependency is a significant issue for these patients but it is compounded by the psychological/emotional dependency needs.

Due to the predominance of young adults in the AIDS population, it is not surprising, as Cuff (1985) points out, that these patients must usually undergo a role reversal. Young adults in this culture are usually concerned with caring for their parents, rather than being cared for. Also, due to the social stigma associated with AIDS, these patients are often denied some of the psychological benefits of the "sick role" that other seriously ill patients receive. The lack of normal support systems and life threatening fears often causes patients to be highly demanding of/dependent on health care staff (Christ & Wiener, 1985). One of the recurring themes identified by Newmark (1984) in dealing with AIDS support groups was the need for comfort and reassurance. Dependency behaviors are altered dramatically by an AIDS diagnosis and warrant evaluation in both categories: physical and psychological.

ELIMINATIVE BEHAVIORS: The goal is the expulsion of

biological wastes and the drive is a biologic necessity (Johnson, 1968, 1980). Derdiarian (1983) identified the main extrapolated dimensions as "quality", the "nature and pattern", and "consequences". The categories derived were (1) gastrointestinal (GI), (2) genitourinary (GU), and (3) integumentary (Derdiarian, 1983). The area of greatest anticipated impact for most AIDS patients would be the GI tract. Chronic, persistent diarrhea may be secondary to viral or parasitic infections, malignancies involving the GI tract, or unknown causes, and can be a major (even life threatening) problem for these patients (Gong, 1985). *Cryptosporidium* (protozoa) which causes a self-limiting (6 day course) of diarrhea in immunocompetent people, may manifest as a profound diarrhea consisting of up to hourly bowel movements resulting in a total fluid loss of 10-15 liters of fluid and electrolytes per day in AIDS patients (CDC, 1982). In this situation the symptoms may persist for months and may result in severe weight loss, malnutrition, and debility (Kovacs & Masur, 1985). Gong (1985) noted that with many of the Central Nervous System (CNS) disorders that occur in AIDS patients, there is a resulting loss of bowel and bladder control. Changes in integumentary elimination might be primarily due to the alteration in nutritional status (dryness of skin, loss of turgor, etc.) and incidence of infections (night sweats,

etc.) secondary to the underlying immunodeficiency.

INGESTIVE BEHAVIORS: The goal of this subsystem is the achievement of satiety for the physical need for food and fluids, and the drive is hunger (Johnson, 1968, 1980). Derdiarian's (1983) work extrapolated the dimensions of ability to "obtain", "assimilate", and to "attain gratification" from eating and/or drinking. The categories derived (Derdiarian, 1983) were (1) ability to physically intake foods, (2) intake-assimilation determinants, and (3) psychosocial determinants. Lang, Spiegel, & Strigle (1985) addressed the special problems that AIDS patients have with eating and nutrition at length. They noted that AIDS patients have eating problems compared with those that many cancer patients face including anorexia, nausea, vomiting, taste changes etc.. Additionally, AIDS patients have frequent and severe problems with candida infections of the oropharynx and esophagus which may require continuous antifungal therapy (Kovacs & Masur, 1985). Lesions in the mouth and esophagus from Kaposi's Sarcoma, candida, or herpes infections make swallowing painful and decrease the desire for food (Cuff, 1985). Dental problems are not infrequent in AIDS patients, yet finding a dentist that will accept and treat an AIDS patient can be a problem in some communities (Lang, Spiegel, and Strigle, 1985). This author proposes that isolation and fear of infecting others

would in many cases impact the psychosocial aspects of eating and mealtimes. If the patient is receiving chemotherapy, all three categories (physical ability to intake, to assimilate, & psychosocial factors) may be impacted by that factor alone (Cuff, 1985).

RESTORATIVE BEHAVIORS: The goal of this subsystem is relief from fatigue and/or to achieve a state of equilibrium by re-establishing or replenishing the energy distribution among the subsystems, and the drive is fatigue and overstimulation (Johnson, 1980). Derdiarian (1983) extrapolated the dimensions of ability to "sleep", "relax", and "maintain physiological equilibrium". The categories utilized were (1) sleep determinants, (2) relaxation determinants, and (3) physiological restorative factors. Forstein (1984) noted that anxiety is a major problem for AIDS patients and that this anxiety frequently leads to sleep disorders, especially insomnia. Forstein describes the anxiety syndrome occurring in AIDS patients as ranging from mild anxiety, responsive to reassurance and education, to a level of paralyzing anxiety secondary to fear of imminent death. The ability for these patients to relax would be impacted by a variety of physical and psychosocial issues. A few physical factors already discussed include blindness, severe diarrhea, and general weakness. Some psychosocial factors discussed include isolation, rejection

by friends and family members, and personality alterations secondary to CNS problems.

An AIDS patient's ability to physically restore his/her body's needs is often significantly altered by the effects of the disease. The severe nutritional deficiencies that result from alterations in the body's Eliminative and Ingestive subsystems may be severe enough to require parental nutrition (Kovacs & Masur, 1985). Fever may significantly increase the metabolic rate further increasing the patient's caloric requirements (Gong, 1985). Inability to get enough air and shortness of breath is frequently a problem for AIDS patients. Kovacs & Masur (1985) noted that diffuse pneumonia is one of the most frequent life threatening processes that brings AIDS patients to medical attention. Treatments such as chemotherapy, interferon and even antibiotics heavily tax patient's ability to get adequate rest. Treatments usually also multiple clinic visits, hospitalizations, and require uncomfortable procedures (Christ & Wiener, 1985).

SEXUAL BEHAVIOR: This subsystem's goal is the engagement of the activities that lead to relief of sexual tension and/or procreation, congruent with gender identity, and the drive is libido (Johnson, 1968,1980). Derdiarian (1983) extrapolated the dimensions of "features and activities characteristic to gender" and "biopsychosocial

determinants of sexual functioning". The categories identified were psychosocial factors and sexual function determinants. This is a subsystem that should reflect changes for nearly all AIDS patients. Since the exchange of body fluids during sexual relations could infect an uninfected partner, usually changes in sexual behavior is demanded. Because of the publicized association between AIDS and homosexuality, many AIDS patients are forced to reveal their homosexuality to family and friends for the first time (Christ Wiener, 1985). A 1983 Newsweek article (Cappola & Zabarskey) referred to a 1982 study which revealed that 4 out of 5 urban gay males had not told their families of their homosexuality. For many gay men, the diagnosis precipitates reliving of the "coming out" process, with exacerbation of the residual, internalized self-hatred (Forstein, 1984). Wolcott, et al., (1985) noted a renewed guilt towards a homosexual lifestyle and internalized negative feelings regarding their sexual orientation. Furstenberg and Olsen (1984) noted that those who have not yet fully accepted their homosexuality may experience an even greater self-rejection. As Forstein (1984) commented: due to the high risk of HIV transmission associated with certain unprotected homosexual behaviors, these patients are likely to face reevaluation of their sexual identity. One of six recurring themes from an AIDS

support group review was the need felt for continuous justification of their sexual identity (Newmark, 1984). These same patients added that this became especially important as they strained to assimilate into what they perceived as a "straight" institution (National Institute of Health).

Another consideration is the body image changes that occur with Kaposi's Sarcoma lesions, chemotherapy, and the general wasting process so characteristic of this disease. These all can cause problems with maintaining one's appearance and thus sexual attractiveness. This is especially traumatic for many of the homosexual patients that have acting, modeling, or other professions where appearance is very important (Buckingham, 1986). Patients have stated that they are so upset that they no longer use mirrors, or look into them only long enough to cover the Kaposi's Sarcoma lesions with make up (Christ & Wiener, 1985).

Changes in regard to sexual functioning impacts all AIDS patients. Sexual activity is lost for some and the sexual act is corrupted as it becomes identified as the mode of transmission of the illness (Rubinow, 1984). Forstein (1984) noted that the fear of giving AIDS to others (especially sexual partners) may result in social withdrawal and isolation from peers and friends. They may feel obligated to abstain from sex yet, Forstein noted, the

stress of diagnosis of AIDS often initiates an intense need for physical contact and emotional intimacy. Complaints of sexual dysfunction are reported (Forstein, 1984) as well as inhibited sexual desire, especially among previously active single men and couples who may be afraid of infecting one another. For patients used to a very active sexual life, abstinence also may represent the loss of an entire social network (Lehman & Russell, 1985). All considering, the impact of AIDS on the sexual subsystem is likely to be very significant.

CHAPTER 4

METHODOLOGY

The Methods Chapter will present concepts and procedures developed and planned for completion of this study. The design, operational definitions, assumptions, sample description, procedures, instrument description, plan for data analysis, and limitations are all addressed.

Design

A descriptive design (nonexperimental) was chosen for this study as the independent variable (diagnosis of AIDS with Kaposi's Sarcoma) could not be manipulated. Since the study attempts to describe characteristics of a particular population (individuals diagnosed with AIDS and Kaposi's Sarcoma), a descriptive design choice is considered appropriate (Murdaugh, 1986). Polit and Hungler (1983) define descriptive research as: "Research studies that have as their main objective the accurate portrayal of the characteristics of persons, situations, or groups and the frequency with which certain phenomena occur"(p.613). It is hoped that this study will provide a foundation for further research, a characteristic expectation of descriptive research.

Advantages of this research design include the fact that it fits the situation of describing relationships among variables defined in a conceptual framework

(Murdaugh, 1986). Also, since it is free of some of the artificial aspects of experimental research, it may be more generalizable to realistic settings (Polit & Hungler, 1983).

Weaknesses of this design include the lack of control over the independent variable (diagnosis) and the inability to truly randomize subjects, increasing the "self-selection" problem described by Polit and Hungler (1983). A major limitation of any descriptive research is its inability to provide insight into why certain phenomena or behaviors occur (Polit & Hungler, 1983). It provides only documentation of the facts, without the ability to explain or predict future responses.

Murdaugh (1986) notes the importance of providing operational definitions for each variable being studied in measurable terms. The operational definitions utilized in this study follow:

Operational Definitions

Achievement Subsystem

For the purpose of this study, achievement will be defined as the ability to master or control one's self or environment. This includes accomplishments appropriate for age and sociocultural position, the ability to delay pleasure to achieve another goal, the development of identity and self-concept, and ability to care for one's own

affairs of daily living (Auger, 1976; Grubbs, 1974) The achievement subsystem, in this study is synonymous with motivation and will be explored in terms of physical and emotional dimensions which may interfere with, or modify the ability to achieve/be motivated.

Change will be a perceived alteration of the Achievement Subsystem: related physical or emotional aspect of the subject's life in comparison to the time preceding the onset of the disease diagnosis and/or its treatment. Changes will be measured by those items acknowledged by the subject, as being changed and those added to this column by the subject during the interview. Each change will be further analyzed by the subject in terms of increase/decrease, positive/negative, and its relative importance by assigning a number on a scale of 1-100.

Variables in the person will be the physical or psychological/emotional ability to achieve goals. These will be measured in terms of change via the subject's choice of changes listed on the instrument or by changes which the subject adds.

Incentive will be the value or worth one places on the achievement of a specific goal. This will be measured in terms of change via the subject's choice of changes listed on the instrument or by changes which the subject adds.

Affiliative Subsystem

For the purposes of this study, affiliation will be the ability to relate or belong to something or someone other than one's self; to achieve intimacy and inclusion. This includes relationships to persons with whom the person is intimate and involves interpersonal skills such as sharing, reaction strangers, approach vs. avoidance of social interactions, and access to sources to meet group inclusion needs (family, residence, work, clubs, church). This further involves the general manner of relating (friendly, shy, hostile), an awareness of others' reactions or feelings, and the influence of significant others on behavior and beliefs (Grubbs, 1974).

Change will be a perceived alteration of the Affiliative Subsystem: related physical or emotional aspects of the subject's life in comparison to the time preceding the diagnosis or onset of the disease and/or its treatment. Changes will be measured by those items acknowledged by the subject, as being changed and those added to this column during the interview. Each change will be further analyzed by the subject in terms of increase/decrease, positive/negative, and its relative importance by assigning a number on a scale of 1-100.

Family relationships will be involvements and interactions with individuals the subject perceives as "family".

These will be measured by the subject's choice of changes offered in the interview as well as those changes added by the subject at the end of the "Changes" column. Each change will be further analyzed by the relative position on a scale of 1-100.

Close relationships will be involvements and interactions with individuals the patient perceives as close to him or important to him other than "family". These will be measured by documenting which items of "Change" the subject perceived or added.

Social and group relationships will be involvements and interactions with persons encountered in group activities. These will be measured by the subject's choice of changes offered (listed on the worksheet), as well as those added by the subject.

Aggressive-Protective Subsystem

For the purposes of this study, aggression/protection will be the protection of self or others from real or imagined threatening objects, persons, or ideas; achievement of self-preservation and self-assertion.

Threat will be a situation in which a person perceives himself, important others, or his goal, to be in jeopardy.

Change will be a perceived alteration of the Aggressive-Protective Subsystem: related physical or emotional aspects of the subject's life in comparison to the

time preceding the diagnosis or onset of the disease and/or its treatment. Changes will be measured by those items listed that are acknowledged as being changed by the subject, and those added by the subject, during the interview. Each change will be further analyzed by the subject in terms of increase/decrease, positive/negative, and its relative position on a scale of 1-100.

Physical response to threat will be the way the body reacts to any real or imagined threat such as communicating verbally, being mobile, conserving or dispensing energy, and autonomic responses. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Emotional response to threat will be the way in which an individual feels about and reacts to any real or imagined threat such as expressions of anger, fear, or frustration, and how one provides emotional support, security, and guidance to family and important others. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Cognitive response to threat will be the thought processes used by an individual to react to any real or imagined threat such as decision making, ability to concentrate, and the ability to perform intellectual skills like reading and writing. To be measured by subjects

choice of perceived changes, both listed in the instrument and added by the subject.

Dependency Subsystem

For the purpose of this study, dependence will be an expression or behavior that serves to regulate the assistance of persons and/or objects in one's environment.

Change will be a perceived alteration of the Dependency Subsystem: related physical or emotional aspects of the subject's life in comparison to the time preceding the diagnosis or onset of the disease and/or its treatment. Changes will be measured by those items listed on the instrument that are acknowledged by the subject, as being changed and those added by the subject during the interview. Each change will be further analyzed by the subject in terms of increase/decrease, positive/negative, and its relative position on a scale of 1-100.

Physical dependency will be the reliance on someone or something for aid in accomplishing mechanical or management tasks. These will be measured by the subject's choice of offered changes and those added by the subject.

Emotional dependency will be the reliance on someone or something for psychological support and security. These will be measured by the subject's choice of offered changes and those added by the subject.

Eliminative Subsystem

For the purpose of this study, elimination will be the ability to reduce a perceived state of tension or pressure existing within an individual via externalizing the internal environment. Elimination is limited to physiological mechanisms for removal of body wastes such as defecation, urination, menstruation, or unusual discharges.

Change will be a perceived alteration of the Eliminative Subsystem: related physical or emotional aspects of the subject's life in comparison to the time preceding the diagnosis or onset of the disease and/or its treatment. Changes will be measured by those items listed that are acknowledged as being changed by the subject, and those added by the subject, during the interview. Each change will be further analyzed by the subject in terms of increase/decrease, positive/negative, and its relative position on a scale of 1-100.

Gastrointestinal will be the eliminative processes and excretory products of the alimentary canal. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Genitourinary will be the eliminative processes and excretory products of the urinary and genital systems. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Skin will be the eliminatory processes and excretory products of the integument. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Ingestive Subsystem

For the purpose of this study, ingestion will be the ability to and the desire for taking in and digesting of food and drink. The physiological mechanisms include the ability to chew, swallow, salivate, and digest. The desire for ingestion includes enjoyment of food and drink, altered food and fluid tolerance, preferences, and appetite.

Change will be a perceived alteration of the Ingestive Subsystem: related physical or emotional aspects of the subjects life in comparison to the time preceding the diagnosis or onset of the disease and/or treatment. Changes will be measured by those items listed that are acknowledged as being changed by the subject, and those added by the subject, during the interview. Each change will be further analyzed by the subject in terms of increase/decrease, positive/negative, and its relative position on a scale of 1-100.

Ability to ingest will be the physical capacity to "take in". To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Ability to digest will be the capacity to absorb food and drink. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Desire for ingestion will include one's appetite and dietary preferences. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Restorative Subsystem

For the purposes of this study, restoration will be the ability to maintain or reestablish energy balance throughout to body via transforming or redistributing energy according to the demands of the various subsystems. It includes homeostasis of both physical and emotional energy. Adequate sleep, rest, and relaxation interact here to 1) relieve fatigue, 2) renew energy for future activity, and 3) reduce "physiological fatigue".

Change will be a perceived alteration of the Restorative Subsystem: related physical or emotional aspects of the subject's life in comparison to the time preceding the diagnosis or onset of the disease and/or its treatment. Changes will be measured by those items listed that are acknowledged as being changed by the subject, and those added by the subject, during the interview. Each change will be further analyzed by the subject in terms of

increase/decrease, positive/negative, and its relative position on a scale of 1-100.

Sleep patterns will be the natural, periodic suspension of consciousness during which the body is restored. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Rest/relaxation will be the leisure activities and other stimuli that contribute to the restful, restored feelings associated with these activities. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Energy in bodily processes will be the energy available for normal regulatory functions of the body system. To be measured by subject's choice of perceived changes, both listed in the instrument and added by the subject.

Sexual Subsystem

For the purposes of the this study, sexual will refer to a group of behaviors whose function is to establish and fulfill the environmental expectations associated with one's biological and psychological gender, including, but not limited to procreation. It includes forms of sexual gratification and the development and maintenance of a sexual identity.

Change will be a perceived alteration of the Sexual Subsystem: related physical or emotional aspects of the

subject's life in comparison to the time preceding the diagnosis or onset of the disease and/or its treatment. Changes will be measured by those items listed that are acknowledged as being changed by the subject, and those added by the subject, during the interview. Each change will be further analyzed by the subject in terms of increase/decrease, positive/negative, and its relative position on a scale of 1-100.

Sexual identity will be the perception of sex roles and characteristic masculine/feminine behaviors. To be measured by the subject's choice of perceived changes, both listed in the instrument and added by the subject.

Sexual functioning will be the ability to perform or engage in sexual relations which leave one with satisfaction and/or gratification. To be measured by the subject's choice of perceived changes, both listed in the instrument and added by the subject.

Perceived Life Changes

Those items identified by the subject that have, in the subject's opinion, become altered for him since the diagnosis of AIDS was confirmed by a medical physician. The "items" consist of those listed in the "Change" column by the interviewer and those items added by the subject himself.

Adult--an individual person at least 18 years of age.

AIDS Patients

People that are receiving health care following a documented diagnosis of AIDS (Acquired Immunodeficiency Syndrome) that was made in accordance with the current criteria listed by the Center for Disease Control (CDC). Must be judged physically and mentally capable of answering the questions as presented in the DBSM instrument by their physician.

Kaposi's Sarcoma

A multifocal, systemic neoplastic process, histologically characterized by proliferating fibroblastic and microvascular elements (Safai, et al., 1985). Documented for this study by medical record (pathology) reports.

Assumptions

Several assumptions were made with regard to the design of this study. Specifically:

(1) Access to at least 30 AIDS patients meeting the sample criteria, who would agree to share their perceptions by honestly completing the DBSM instrument in an interview format,

(2) The DBSM instrument will be supported as a valid and reliable instrument to describe and measure changes in this population (AIDS patients) as it did with cancer patients,

(3) The judge panel had adequate expertise to predict

the instrument's ability to provide a comprehensive and accurate description of changes in the eight subsystems of the model, as perceived by this population.

Sample

A convenience sample of 30 outpatients was selected from UCLA Medical Center, Los Angeles, who had a diagnosis of AIDS. Originally, the selection variables included (1) 18 to 60 years of age, (2) diagnosed with AIDS at least 8 weeks prior to study participation, (3) able to communicate in English, (4) judged as physically and mentally capable of participating by their physician, and (5) consented to participate in the study. Ultimately, because of the increased access to patients with Kaposi's Sarcoma (KS), as a manifestation of AIDS, a diagnosis of KS was added to the criteria. Although other variables such as infection source, history of opportunistic infections, sources of support and the like, have been identified within populations of AIDS patients, no attempt was made to exclude patients on the basis of these variables. However, that data was collected as part of the intake data and could be utilized for comparison studies at a later date. On the day of participation, the patients were not faced with any new treatment or medical procedure.

Exclusion Criteria

AIDS patients under 18 were excluded to preempt problems with parental consent and to enhance the population's homogeneity. The AIDS diagnosis had to be based on the CDC criteria and had to have been confirmed by a physician at least 8 weeks prior to participation. Time since diagnosis of eight weeks was designated to allow the patients time to experience/assess changes.

Procedures

After obtaining the approval of both the Human Subject Protection Committee at the University of California, Los Angeles, and the primary attending physicians of the two clinics serving AIDS patients at UCLA (see Appendix B), patient recruitment began. The patients were initially approached regarding participation in the study by the interviewer while they were waiting in either the general AIDS Clinic or the Kaposi's Sarcoma Clinic. Each patient was advised that participation required an interview that would take approximately 90 minutes to complete. They were advised that they would be asked questions about eight different aspects of their lives, noting any changes that had occurred since they received their diagnosis of AIDS. Patient's were assured confidentiality and given a choice of time and location for the interview. Generally, they

were asked to chose between returning to UCLA where a private office was utilized, or having the interviewer come to their home. Privacy and comfort for the patient were considered priorities. The majority of the interviews were done as home visits. Two patients requested to meet the interviewer at an alternative location (community park) and this was agreed to as it seemed to best meet their privacy and comfort concerns.

If the interview was done at UCLA, the patients were met at a predetermined familiar location by the interviewer and escorted to interview location. They were made comfortable and offered refreshments during the interview.. The actual interview was completed wherever the patient felt most comfortable, usually in a living room or on a patio. Privacy was maintained throughout the interviews.

After meeting the patient at either UCLA or other predetermined location, a few minutes of small talk were utilized for the interviewer and patient to become acquainted and to attempt to put the subject at ease. At the beginning of each interview, the purpose of the study and basic interview procedure was reviewed and the patient signed the consent. After completing the basic data sheet on each subject, (objective and historical data), the interview was initiated, utilizing the DBSM Instrument. It was explained to the patient, from a standardized content

form, that the eight categories of the instrument were assembled in random order, and that as we started on a new category (subsystem) the general category would be introduced to the patient so that he would have an idea of the subject matter involved. For example, as category 8 was started (Sexual Subsystem), the patient was told: "The following questions relate to how you feel about yourself as a male or female. For example, has there been any change in.....since your diagnosis?" At the end of each specific grouping (designated by a page of the instrument), the patient was asked if there were any other changes, associated with the topic, that they would like to add. If items of change were added, they were further clarified the same way all changes were analyzed by noting specifics of increase/decrease, positive/negative, and the relative importance of the change on a scale of 1-100. The subjects were offered frequent rest periods although few seemed to need or desire them.

Two of the eight subsystems, preselected from a randomized permutation were retested at the end of the interview. It was impractical to retest more than two subsystems as it would risk over-taxing the patient. At the end of the research portion of the interview, all participants were asked if they felt the interview was too long or if any of the questions had upset them in any way.

Instrument

The Derdiarian Behavioral Systems Model (DBSM) Instrument was utilized in this study. Based on Johnson's Behavioral Systems Model for nursing, this instrument measures change as a description of imbalance in the patient's behavioral system, identified and described in a systematic manner as perceived by the patients themselves. The instrument consists of 140 items of physical and psychosocial changes believed to occur in AIDS patients. Specifically, it allows the patient to describe the changes in terms of:

- (1) the perceived existence of change
- (2) the direction of change: increase or decrease
- (3) the quality of change: positive or negative
- (4) the importance of change: its significance 1-100

(Derdiarian & Forsythe, 1983, p.260)

This instrument (DBSM) was developed for and used in identifying and measuring behavioral changes in a population of cancer patients by Derdiarian (1983).

Adjustments made on the DBSM to specify for terminology and points of increased relevance in this population are presented in the Appendix A. The adjusted DBSM was submitted to a judge panel as a test for content validity prior to utilization.

Validity

The content validity of the DBSM instrument was determined by expert (judge) panel agreement. The judge panel consisted of (1) A Clinical Nurse Specialist, MN, experienced in supervising nursing care of AIDS patients, (2) A Medical Social Worker, MSW, assigned to an AIDS Out-patient Clinic, (3) A staff nurse, BSN, (Level III), routinely involved in day-to-day care of AIDS patients, and (4) a patient, diagnosed with AIDS approximately 7 months prior to the panel review. A 98% agreement regarding specific items was achieved. The AIDS patient on the panel suggested that the interviews be done on outpatients (original proposal was for inpatients), preferably in a home setting. He felt that inpatients would have difficulty with time and endurance for interview completion. This suggestion was enacted after a brief pilot study with 2 inpatients indicated that multiple difficulties with patient access, endurance, and comfort could be alleviated by utilizing outpatients.

Reliability

Reliability was evaluated/supported in three ways. First, a standard administration protocol utilizing one interviewer should eliminate concerns about inter-rater reliability. Second, a Pearson Product-moment correlation with the test-retest data (Two subsystems each) should

reflect instrument reliability. Third, after an initial factor analysis, a test of internal consistency will be run (computer assisted). Positive correlation by the internal consistency coefficient would support both reliability and will also indirectly support the validity of the instrument.

Data Analysis

The data analysis approach is presented according to the specific research objectives. The objectives pertaining to the DBSM instrument will be presented first.

One objective of this study was to evaluate the validity, reliability, and comprehensiveness of the DBSM instrument in this population. Percent agreement scores from the initial judge-panel were computed to determine the content validity of this DBSM instrument. Cronbach's alpha coefficients and Pearson Product-moment coefficients were computed to evaluate the internal consistency. The alpha coefficients were used to determine the internal consistency of the overall instrument, as well as that of the subsystems. This measure of internal consistency will also indirectly reflect a degree of construct validity for the DBSM Instrument. As a second measure of the instrument's reliability, the Pearson product-moment coefficients, derived from the test-retest data, were used.

Comprehensiveness of the instrument was evaluated

during the initial judge panel (discussed previously). Additionally, after data collection, three experts (Clinical Nurse Specialists in cancer nursing) familiar with the Johnson Behavioral System Model independently judged the "other" or "additional" changes identified by the subjects during the interview process. The focus here was whether or not the added changes actually fit within the established subsystem framework and operational definitions established. This second judge panel must correlate added changes within the established subsystem framework and operational definitions if the instrument is to be considered truly comprehensive.

The second objective was to describe perceived life changes occurring in this population of AIDS patients. Frequency count distribution of responses were determined to identify changes in the eight behavioral subsystems perceived by the patients. This distribution was determined according to the dimensions of perceived change measured by the instrument as outlined below. Patient responses were initially coded as:

Occurrence:	None as a 0; Occurring as a +1
Direction:	Increase as a +1; Decrease as a -1
Quality:	Positive as a +1; Negative as a -1
Importance:	Continuous scale of 1-100

Limitations

Several recognized limitations exist in this study, a major one being the fact that a convenience sample was utilized to get the number of subjects desired. Since all subjects received care through the University of California, Los Angeles (UCLA), this population is geographically and probably socio-economically and educationally skewed. The support services available to this population are much greater in the Los Angeles area than in many areas of the country, which may act to modify the impact of the disease. Also, even though there are increasing numbers of juvenile and adolescent AIDS patients, this study is restricted to adults.

The small sample size ($N = 30$) limits the statistical interpretation of the data. Although attempts were made to recruit all eligible patients in the two AIDS clinics, most were recruited from the KS specialty clinic resulting in a further specification of the sample population. Only 30% of patients with AIDS develop KS (Safai, et al., 1985) yet 100% of the sample were diagnosed with KS. Additionally, 95% of the AIDS patients with KS in the United States have been homosexual or bisexual men (CDC, 1986b) (correlates with 100% of study participants). These two characteristics of the sample will further limit the generalizability of the findings to adult AIDS patients.

The necessity of limiting the test-retest procedure to two subsystems for each patient limits the degree of generalization one can derive from the findings regarding the reliability of the DBSM Instrument.

CHAPTER 5

RESULTS

The results of this study are presented in the order of the data collection process. Data are presented that relate to the participants first, followed by data relating to the actual instrument. Last, data reflecting the actual perceived life changes, including the occurrence, direction, quality, and importance of those changes, are presented. Due to the tremendous amount of data obtained in this study, this chapter will frequently focus on summarized results. If the reader desires more detailed results, they are available within the Appendices.

Results Relating to the Participants

Data was gathered by interview from 30 participants over a 5 month period. Two individuals declined participation when first approached due to distance from home and travel difficulties (commuting from Bakerstfield, CA and Las Vegas, NV). Two individuals chose not to participate after the initial meeting, when specifying a time and location for the interview became inconvenient. One interview was dropped from the study when it became apparent that the patient was dealing with neurological impairment, making interview completion virtually impossible. After an hour of conversation, this patient was told that the interview was completed and thanked for

his participation. As the study progressed, it became apparent that nearly all the participants had Kaposi's Sarcoma (KS) as a manifestation of AIDS. Therefore, three interviews of patients without KS were dropped to make the sample more homogenous. One interview lacked the retest portion because completing the basic interview took approximately four and a half hours. This particular patient loved the interview (talked incessantly) and denied any fatigue, but after that time period, the interviewer was exhausted.

The population ranged in age from 24 to 53 with a mean of 39.0 years. As noted in Table 1, 50% of the population was between 31 and 40 years old and a full 86% fell between 31 and 50 years of age. All participants were male, the majority (86.7%) being Caucasian. The remaining 13.3% were Hispanic. Table 1 reveals a relatively high level of education for this population. All were high school graduates; three (10%) held doctorates. The mean level of education was that of a college graduate. The sexual orientation of the population was predominantly homosexual (90%). The remaining 10% of the population identified themselves as bisexual.

Referring again to Table 1, it is noted that only 66.7% of the population told their relatives of their diagnosis (AIDS), compared to the 80% that shared this news

Table 1

Sample by Variables (N = 30)

Variable	Number	%
<u>Age</u>		
20-30 years	3	10.0
31-40 "	15	50.0
41-50 "	11	36.7
51-60 "	1	3.3
<u>Sex</u>		
Male	30	100.0
<u>Race</u>		
Caucasian	26	86.7
Hispanic	4	13.3
<u>Education</u>		
High School	2	6.7
1-2 yrs. College	13	43.7
College Grad.	7	23.3
Post Grad. Courses	4	13.3
Master's Degree	1	3.3
Doctorate Degree	3	10.0
<u>Sexual Orientation</u>		
Heterosexual	0	0.0
Homosexual	27	90.0
Bisexual	3	10.0

Table 1 (Continued)

Sample by Variables (N = 30)

Variable	Number	%
<u>Told Relatives Diagnosis</u>		
Yes	20	66.7
No	10	33.3
<u>Told Friends Diagnosis</u>		
Yes	24	80.0
No	6	20.0
<u>Support Sources</u>		
Family	22	73.3
Friends	29	96.7
Spouse/Lover	16	53.3
Support Groups	14	46.7
Therapist	11	35.7
Physician	27	90.0
Nurse	20	66.7
Clergy	10	33.3
Other	13	43.3

with friends. Additionally, when noting which sources of support this population utilized in coping with the AIDS diagnosis (see Table 1), "friends" were cited 96.7% of the time. "Family" was cited 73.3% of the time and "spouse or lover" was noted as a support only 53.3% of the time. Interestingly, these outpatients stated that their physician was a primary source of support for 90% of them and that "nurses" provided support for 66.7%. All other individual sources of support (support groups, clergy, other) were each utilized by less than 46.7% of this population. Additional sources of support were added by 13 (43.3%). Sources cited included employers, coworkers, a homeopathic physician, metaphysicians, psychics, and a lab tech. Also included were: the Buddy Program at AIDS Project, Los Angeles (APLA), the APLA Hot Line, reading literature, pets, and a positive attitude.

This population is further described by Table 2 which notes the medical variables. A wide range of "time since diagnosis" was represented by 2 to 48 months. Nearly half (46.7%) had been diagnosed 5 to 12 months prior to the interview. The mean time since diagnosis was 13.4 months. Within the population of 30 patients with KS, 12 patients had been diagnosed with at least one opportunistic infection in addition to the KS. The majority (66.7%) had not required hospitalization since they were diagnosed. Six

Table 2

Sample by Medical Variables (N = 30)

Variable	Number	%
<u>Time Since Diagnosis</u>		
2-4 months	4	13.3
5-8 "	9	30.0
9-12 "	5	16.7
13-18 "	5	16.7
19-24 "	2	6.7
25-36 "	3	10.0
37-48 "	2	6.7
<u>Diagnosed Infections</u>		
Kaposi's Sarcoma (KS)	30	100.0
KS & Opportunistic		
Infections	12	40.0
<u>Hospitalizations^a</u>		
None	20	66.7
Once	6	20.0
Twice	2	6.7
More than 4 times	2	6.7

^aHospitalizations since AIDS diagnosis was made.

patients (20%) had been hospitalized once since diagnosis; two (6.7%) had been hospitalized more than four times.

Results Relating to the Instrument

Validity

As discussed previously, a four member judge panel reviewed the adjusted DBSM Instrument prior to the interview process. They delivered a 100% agreement on the relationship between the operational definitions and theoretical framework. A 98% agreement on the correlation between the items on the instrument and operational definitions was obtained (only one item was revised). The details of this judge panel's findings can be found in Appendix D.

Comprehensiveness

The initial judge panel was 98% in agreement that the DBSM Instrument was comprehensive. The addition of one item resulted in 100% agreement prior to data collection. The comprehensiveness of this instrument was reviewed again at the conclusion of the data collection. The results of this follow-up review reflected the personal experiences of this population.

During data collection, participants were encouraged to add any changes that they had experienced, which they felt had not been addressed. A total of 76 different items were added by the 30 participants. These items were then

seperately reviewed by a second judge panel consisting of three oncology clinical nurse specialists, all experienced with the Johnson Behavioral Systems Model (JBSM). The primary researcher was one of the three reviewers. The goal of this second judge panel was to determine how many, if any, of the 76 added items were actually covered by other areas of the instrument. Also which, if any, needed to be added to make the DBSM Instrument truly comprehensive for this population.

This second judge panel determined that all 76 additional items could be addressed within the existing 8 Subsystems/21 Categories of the DBSM Instrument. However, it was also determined that to be truly comprehensive, four items needed to be added to the instrument. Although there was some difference of opinion regarding where the items should be added (which category), there was a 100% agreement on what needed to be added for this population. The four items consisted of: (1) Concern over society's attitude towards AIDS, (2) Ability to establish new relationships, (3) Use of alcohol, tobacco, or other recreational drugs for pleasure or relaxation purposes, and (4) Feelings towards death and dying. This second judge panel surmised that with these four additional items, the DBSM Instrument would be 100% comprehensive. It was judged 97% comprehensive, as utilized, in this study.

Reliability

A computer-assisted test of internal consistency, using the alpha coefficient, was completed for all of the responses. Separate scores were generated for each aspect of the changes identified: Increase/Decrease (I/D), Positive/ Negative (P/N), and Importance Scores (IMP). Although a summary of the findings (see Table 3) will be frequently referred to, a more detailed account of the alpha scores can be found in Appendix E. Additionally, a test-retest Pearson correlation was completed as previously described in the Methods chapter.

Internal Consistency of Entire Instrument. The alpha scores for the overall DBSM Instrument (All Subsystems) were quite significant, ranging from 0.84 (I/D) to 0.94 (P/N). The alpha score for the IMP aspect of the data was 0.92. As the alpha scoring reflects smaller units of the DBSM Instrument (subsystems and categories), the scores generally decrease.

Internal Consistency Within Subsystems. Table 3 lists the mean alpha scores for each group of responses (I/D, P/N, & IMP) noting the score of each subsystem within each group. The I/D group displayed subsystem alpha scores ranging from 0.44 to 0.73. The P/N group had subsystem alpha scores ranging from 0.63 to 0.85. Last, the IMP group revealed subsystem alpha scores ranging from 0.68 to 0.85.

Table 3

Summary of Internal Consistency Coefficient Findings

Type of Response	Mean ϕ	Range ^a
<u>Increase/Decrease</u>		
ALL SUBSYSTEMS	0.84	0.44—0.73
Achievement	0.63	0.49—0.56
Affiliative	0.54	0.27—0.65
Aggressive/Protective	0.73	0.30—0.65
Dependency	0.61	0.40—0.41
Eliminative	0.68	0.04—0.73
Ingestive	0.70	0.42—0.54
Restorative	0.44	-0.11—0.55
Sexual	0.73	0.55—0.59
<u>Positive/Negative</u>		
ALL SUBSYSTEMS	0.94	0.63—0.85
Achievement	0.75	0.63—0.71
Affiliative	0.82	0.65—0.86
Aggressive/Protective	0.85	0.69—0.79
Dependency	0.68	0.51—0.68

Note. Number of cases used to calculate these scores varied from 26-30. Refer to Appendix C for specific details.

^aAlpha scores for categories within the listed subsystem.

Table 3 (Continued)

Summary of Internal Consistency Coefficient Findings

Type of Response	Mean ϕ	Range ^a
<u>Positive/Negative</u>		
Eliminative	0.63	-0.06—0.72
Ingestive	0.83	0.52—0.74
Restorative	0.78	0.50—0.73
Sexual	0.84	0.69—0.78
<u>Importance</u>		
ALL SUBSYSTEMS	0.92	0.68—0.85
Achievement	0.68	0.47—0.67
Affiliative	0.85	0.72—0.83
Aggressive/Protective	0.75	0.46—0.80
Dependency	0.81	0.56—0.81
Eliminative	0.78	-0.08—0.78
Ingestive	0.80	0.52—0.70
Restorative	0.81	0.50—0.72
Sexual	0.85	0.65—0.87

^aAlpha scores for categories within listed subsystem.

To summarize, all but two of these alphas were ≥ 0.61 (see Table 3).

Internal Consistency Within Categories. As the instrument is split down further, into categories, the alpha scores are less significant. In Table 3, the "Range" portrays the span of alpha scores for the categories within each subsystem. Although several low alpha scores exist (even negative values), a review of the detailed information in Appendix C show that 47 (76%) of the alpha scores for the categories were ≥ 0.50 . One category within the Eliminative Subsystem, 5B (genitourinary activity), had consistently low alpha scores: -0.08 to 0.04. It should be noted that this category contained only 4 items and had a response rate of only 7.5%. This was, by far, the lowest response rate of any category in the instrument.

Test-Retest Pearson Correlation. A two-tailed Pearson correlation was completed utilizing the two subsystem retests accomplished with 29 of the 30 participants. A detailed listing of the correlation results can be found in Appendix G (Table 6). Overall, the correlations are quite good. However, several very low, or even negative, correlations will be noted throughout the table. The true reason for these occasional low or negative values is, at present, unknown. A possible explanation for variations in the magnitude of the correlations might be the small sample

size ($n = 0-9$). The altered direction (negative values) of some correlations might be due to a number of causes. First, the individual item may be faulty in its reliability. Second, the item may be emotionally charged for the patient causing other variables to impact the response, such as with certain items in the Sexual Subsystem. Third, the fact that the retest was given immediately after completion of the entire interview could impact the response several ways. The patient had then been through the entire instrument and might be thinking differently than when he answered the questions earlier. Also, fatigue may be a substantial factor as up to two hours of questioning may have preceded the retest. A summary of the results by subsystem follows.

In the Achievement Subsystem ($n = 6$) the I/D group had values ranging from $\underline{r} = .42$ ($\underline{p} = .41$) to $\underline{r} = 1.00$ ($\underline{p} = .00$), with a median of $\underline{r} = .91$ ($\underline{p} = .01$). The P/N group ranged from $\underline{r} = .29$ ($\underline{p} = .57$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .87$ ($\underline{p} = .03$). Last, the IMP group had a range of $\underline{r} = .21$ ($\underline{p} = .69$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .77$ ($\underline{p} = .08$).

In the Affiliative Subsystem ($n = 7$) the I/D group had values ranging from $\underline{r} = -.17$ ($\underline{p} = .72$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .81$ ($\underline{p} = .03$). The P/N group ranged from $\underline{r} = -.17$ ($\underline{p} = .72$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a

median of $\underline{r} = .88$ ($\underline{p} = .01$). Last, the IMP group had a range of $\underline{r} = -.21$ ($\underline{p} = .65$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .75$ ($\underline{p} = .05$).

In the Aggressive/Protective Subsystem ($\underline{n} = 6$) the I/D group had values ranging from $\underline{r} = .37$ ($\underline{p} = .48$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .96$ ($\underline{p} = .00$). The P/N group ranged from $\underline{r} = .58$ ($\underline{p} = .23$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .85$ ($\underline{p} = .06$). Last, the IMP group had a range of $\underline{r} = .18$ ($\underline{p} = .74$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .85$ ($\underline{p} = .03$).

In the Dependency Subsystem ($\underline{n} = 9$) the I/D group had a range of values from $\underline{r} = .35$ ($\underline{p} = .36$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = 1.00$ ($\underline{p} = .00$). The P/N group ranged from $\underline{r} = .57$ ($\underline{p} = .11$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .90$ ($\underline{p} = .05$). Last, the IMP group had a range of $\underline{r} = .26$ ($\underline{p} = .50$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .97$ ($\underline{p} = .00$).

The Eliminative Subsystem had an \underline{n} value of 7; item 5B-4 was not included. The I/D and P/N group correlation values both ranged from $\underline{r} = .65$ ($\underline{p} = .12$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = 1.00$ ($\underline{p} = .00$). The IMP group in this subsystem ranged from $\underline{r} = -.17$ ($\underline{p} = .72$) to $\underline{r} = 1.00$ ($\underline{p} = .00$), but also had a median of $\underline{r} = 1.00$ ($\underline{p} = .00$).

In the Ingestive Subsystem, \underline{n} had a value of 7 for categories A and B, and a value of 6 for category C. The

I/D group had values that ranged from $\underline{r} = .55$ ($\underline{p} = .20$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = 1.00$ ($\underline{p} = .00$). The P/N group ranged from $\underline{r} = .50$ ($\underline{p} = .31$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .93$ ($\underline{p} = .01$). Last, the IMP group had values ranging from $\underline{r} = .03$ ($\underline{p} = .96$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .95$ ($\underline{p} = .00$).

The Restorative Subsystem's ($\underline{n} = 9$) I/D values ranged from $\underline{r} = .00$ ($\underline{p} = 1.00$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .90$ ($\underline{p} = .00$). The P/N group ranged from $\underline{r} = -.75$ ($\underline{p} = .02$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .76$ ($\underline{p} = .02$). Last, the IMP group had values ranging from $\underline{r} = -.13$ ($\underline{p} = .75$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .89$ ($\underline{p} = .00$).

In the Sexual Subsystem \underline{n} had a value of 7 for all items except 8B-7 where $\underline{n} = 6$. The I/D group had correlation values that ranged from $\underline{r} = .65$ ($\underline{p} = .12$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .75$ ($\underline{p} = .05$). The P/N group had values ranging from $\underline{r} = .06$ ($\underline{p} = .90$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .90$ ($\underline{p} = .01$). Last, the IMP group ranged from $\underline{r} = .24$ ($\underline{p} = .60$) to $\underline{r} = 1.00$ ($\underline{p} = .00$) with a median of $\underline{r} = .70$ ($\underline{p} = .18$).

Results Pertaining to the Perceived Life Changes

The perceived life changes reported by this population are reported in several ways. Each item of the instrument was scored regarding its reference to change in the

tion of change (increase/decrease), (3) quality of change (positive/negative), and (4) importance of change. The method of processing the results and summary of those results will be presented in this section. This data for each of the 140 items of the DBSM Instrument is available in Appendix F.

Occurrence of Change

The occurrence of change was evaluated by noting whether or not the patient responded to an item as being changed. If the patient noted no change in the item, a line was drawn through the item and the interviewer moved on the next item. The number of responses (denoting a change) were compiled for each item: # of CHANGES. To clarify the meaning of that number, it was converted to a percentage of responses (% of CHANGES), considering the total possible number of responses (changes). When calculating these results for specific items, N was always equal to 30. These results were then summarized according to categories and subsystems. The summary of these results are in Table 4 (For individual item results see Appendix F).

The entire DBSM Instrument identified a total of 140 perceived life changes for this population. The results of the 140 items are as follows: 100 items were changed, 40 items were not changed, and 10 items were not answered.

Table 4

Summary of Perceived Changes (N = 30)

SUBSYSTEM	MEAN VALUES OF RESPONSES			
	CHANGES	I(+1)	P(+1)	Importance
	# (%)	or D(-1)	or N(-1)	(1-100)
<u>Achievement</u>				
1A Physical/mental ability	79(39%)	-.27	-.24	30.2
1B Importance of achieving	114(63%)	+.21	-.02	42.7
TOTAL 1A & 1B	185(51%)	-.03	-.13	36.5
<u>Affiliative</u>				
2A Family relation factors	112(53%)	+.41	+.42	39.5
2B Friends/relatives relation factors	120(50%)	+.20	+.20	36.8
2C Group relation factors	61(41%)	+.06	+.16	28.5
TOTAL 2A, 2B, & 2C	293(49%)	+.24	+.27	35.7
<u>Aggressive/Protective</u>				
3A Physical ability to protect	100(40%)	+.00	+.00	30.0

Note: Mean values of responses are based on a scale of 1 to 100, where 1 = not at all important and 100 = very important.

Table 4 (Continued)

Summary of Perceived Changes (N = 30)

SUBSYSTEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1) or D(-1)	P(+1) or N(-1)	Importance (1-100)

Aggressive/Protective

3B Maintaining emotional stability	131(73%)	-.04	+.08	49.7
3C Cognitive ability to protect	77(43%)	-.03	-.01	30.2
TOTAL 3A, 3B, & 3C	318(51%)	-.02	-.13	33.5

Dependency

4A Functional physical dependency	118(44%)	+.33	-.24	29.5
4B Functional emotional stability	76(51%)	+.48	+.17	35.3
TOTAL 4A & 4B	194(46%)	+.39	-.10	31.6

Eliminative

5A Intestinal activity	46(22%)	+.20	-.21	11.7
5B Uroinary activity	9(4%)	+.08	-.03	1.1
5C Integumentary activity	40(38%)	+.38	-.38	19.
TOTAL 5A, 5B, & 5C	95(32%)	+.24	-.23	12.2

Table 4 (Continued)

Summary of Perceived Changes (N = 30)

SUBSYSTEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%)	or D(-1)	or N(-1)
<u>Ingestive</u>				
6A Physical ability to				
obtain & process food	31(15%)	-.12	-.13	7.2
6B Ability to maintain				
eating customs	61(41%)	+.07	-.04	21.9
6C Ability to enjoy food	99(41%)	+.15	.00	22.2
TOTAL 6A, 6B, & 6C	191(32%)	+.03	-.06	16.9
<u>Restorative</u>				
7A Amount/quality of				
sleep & dreams	67(37%)	-.05	-.17	21.0
7B Ability to relax	121(58%)	+.03	+.01	36.8
7C Physiological and func-				
tional equilibrium	68(38%)	-.01	-.32	22.6
TOTAL 7A, 7B, & 7C	256(45%)	-.01	-.15	27.3
<u>Sexual</u>				
8A Physical activity char-				
acteristic of gender	105(50%)	-.26	-.30	38.3

Table 4 (Continued)

Summary of Perceived Changes (N = 30)

SUBSYSTEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
	# (%)	or D(-1)	or N(-1)	(1-100)

Sexual

8B Biopsychosocial deter-

minents of sexual func-

tioning

172(72%)

-.51

-.49

50.2

TOTAL 8A & 8B

277(62%)

-.39

-.40

44.6

ALL SUBSYSTEMS

TOTAL

1849(44%)

+.06

-.11

29.1

Sexual Subsystem reflected the highest occurrence of change, with a total of 277 (62%) responses to the possible changes. Achievement and Aggressive/Protective Subsystems were next, each reflecting a 51% response to the possible changes. The Eliminative Subsystem reflected the least occurrence of change with a total of 135 (25%) responses to the possible changes.

When the subsystems are broken down into the 21 categories of the DBSM Instrument, more specific information regarding occurrence of change is revealed. Category 3B (Maintaining emotional stability) had the greatest percentage of change with 73% of the possible changes occurring. 8B (Biopsychosocial determinents of sexual functioning) was a close second with 72% of the possible changes occurring. Category 1B (Importance of achieving) was next with 63% of the possible changes occurring, followed by 7B (Ability to relax) at 58% and 2A (Family relationship factors) at 53%. At the opposite end of the spectrum, category 5B (Genitourinary activity) reflected the least changes, noting only 8% of possible changes. Category 6A (Physical ability to obtain and process food) also had few changes with only 15% of the possible changes noted. Category 5A (Intestinal activity) and 7A (Amount/quality of sleep & dreams) had 22% and 38% of the changes, respectively.

Although evaluating the occurrence of changes by category provides greater insight into the types of changes experienced by this population, item analysis renders even more specified information. In reviewing the occurrence of change among the 140 items of the instrument (Data located in Appendix D), certain figures draw notice. The single item with the greatest percentage of change was 5C-1 (Skin irritations/itching, etc), with a 93% response rate. This was followed by 1B-1 (Importance of planning/pursuing new ventures) at 86%. Items 3B-2 (Ability to handle anger, fear, frustration), 3C-4 (Ability not to be hard on yourself), 4B-3 (Reliance on health professional for information), and 8B-5 (Frequency of sexual activities), all had an 83% rate of change. These were followed by 3A-5 (Infection susceptibility), 8B2 (Sexual physical satisfaction), and 8B-6 (Methods of satisfying sexual desires or needs), which all reported an 80% occurrence of change.

The individual items which reported the least amount of change were concentrated in category 5B (Genitourinary activity). Item 5B-4 (Menstrual flow) had no change since the population was 100% male. This item was therefore dropped from other statistical analyses (alpha coefficients). Items 6A-6 (Ability to get or eat prescribed foods and 6A-7 (Ability to tolerate food/fluids by mouth)

had no changes identified. Items 5B-3 (Pain when urinating) and 5B-5 (Penile discharges) each showed only 3% (1 participant) noting changes. Items 5B-1 (Amount, frequency, color, discomfort of urination) and 6B-2 (Ability to keep food down) exhibited a 7% occurrence of change. Other items with a lower incidence of change include 5B-2 (odor of the urine/discharges) and 5C-5 (Dry itchy eyes), both reporting a 17% incidence of change (5 participants).

The remaining 122 items on the DBSM Instrument elicited a percentage of occurrence ranging from 20% (6 responses) to 77% (23 responses). The details on these items are available in Appendix F.

Direction of Change (Increase/Decrease)

The direction of change was evaluated by having the participant rate each change he experienced as an increase or a decrease from the norm (prior to receiving AIDS diagnosis). Responses were then scored with a (+1) for "Increase", a (0) for "Undecided", and a (-1) a "Decrease". "Undecided" was used as a response when the participant stated the item had changed, but that he could not choose between the "Increase" and "Decrease" responses. After each response was scored accordingly, means were obtained to describe the sample as a whole. This was accomplished for each item (see Appendix F) and then summarized by

categories and subsystems (see Table 4).

When all 140 items (8 subsystems) of the DBSM are considered, the mean direction of change score is +0.06. This has more significance when the data is studied by subsystems. Changes in the Dependency Subsystem revealed the greatest increase of activity with $\underline{M} = +0.39$. The Affiliative and Eliminative Subsystems followed with $\underline{M} = +0.24$. Changes in the Sexual Subsystem reflected the greatest decrease in activity with a $\underline{M} = -.039$. All other subsystems had mean scores between -0.03 and +0.03.

Examination of the I/D means by category provides more detailed information regarding the increase or decrease within the subsystems. The category whose changes reflected the highest increase in activity was 4B (Functional emotional stability) with $\underline{M} = +0.48$. Category 2A (Family relations factors) followed with $\underline{M} = +0.41$. Next came 5C (Integumentary activity) at +0.38 and 4A (Functional physical dependency) at +0.33. Changes in category 8B (Biopsychosocial determinants of sexual functioning) reflected the greatest decrease in activity with a $\underline{M} = -.051$. Categories 1A (Physical & mental ability to achieve) and 8A (Physical activity characteristic of gender) followed with mean scores of -0.27 and -0.26, respectively. The mean scores denoting direction of change for the 14 other categories all fell between -0.12 and

+0.21 (see Table 4).

Examining I/D means for the individual items provides the most specific description of the direction of change. The single item reflecting the greatest mean increase was 5C-1 (Skin irritations, itching) with $\underline{M} = +0.93$. Items 3A-7 (Irritation/inflammation of skin or mucous membranes), 4B-3 (Reliance on health professionals for information), and 6C-2 (Reason why you eat) all indicated a considerable increase with $\underline{M} = +0.77$. The perceived increased risk of infection in this population was reflected by a mean score of +0.67 for item 3A-5 (Infection susceptibility). The greatest mean decreases in items were clustered in the Sexual Subsystem. Item 8B-5 (Frequency of sexual activities) showed the largest decrease with a $\underline{M} = -0.83$. This was followed by 8B-2 (Sexual physical satisfaction) with $\underline{M} = -0.80$, and 8B-3 (Physical ability to engage in sexual acts) at $\underline{M} = -0.73$. Item 8A-4 (Ability to perform in usual gender role-male lover) was also markedly decreased with $\underline{M} = -0.67$. The remaining 131 items of the DBSM Instrument reflected I/D changes with mean scores between -0.63 and +0.63 (see Appendix F).

Quality of Change (Positive/Negative)

The quality of change was evaluated by having the participant rate each change he experienced as either a positive or negative change in his life. Responses were then

scored as (+1) for "Positive", (0) for "Undecided", and (-1) for "Negative". "Undecided" was used as a response when the participant stated the item had changed, but that he felt it was neither a "Positive" or "Negative" change in his life. After each response was scored accordingly, means were obtained to describe the sample as a whole. This was accomplished for each item (see Appendix F) and then summarized by categories and subsystems (see Table 4).

When the mean quality (P/N) scores of the entire population for the overall DBSM Instrument are averaged, a $\bar{M} = -0.11$ is obtained. A look at the mean P/N scores from the various subsystems provides more specific information. The Affiliative Subsystem reflected the most positive changes with $\bar{M} = +0.27$, and was actually the only subsystem to have a positive mean score for quality of change. The Sexual Subsystem had the most negative changes, reporting a $\bar{M} = -0.40$. The Eliminative Subsystem followed with $\bar{M} = -0.23$. The other 6 subsystems had mean P/N scores between -0.06 and -0.15.

Examining the mean P/N scores of the categories will provide more detailed information regarding the quality of changes in this population. Most of the categories with positive mean scores were found in the Affiliative Subsystem. The most positive mean score was 2A (Family relation factors) with a $\bar{M} = +0.42$. Category 2B

(Friends/relatives, relation factors) was next with $\underline{M} = +0.20$. Changes in 4B (Functional emotional stability) were also more positive with $\underline{M} = +0.17$. The most negative mean score was category 8B (Biopsychosocial determinants of sexual functioning) with $\underline{M} = -0.49$. Categories 5C (Integumentary activity) and 3A (Physical ability to protect) followed with $\underline{M} = -0.38$ and $\underline{M} = -0.35$, respectively. Changes in category 7C (Physiological and functional equilibrium) were perceived as negative, with $\underline{M} = -0.32$. The other 14 categories had mean P/N scores between -0.30 and $+0.16$ (See Table 4).

Again, if one changes the focus to that of individual items, more detailed information becomes available (see Appendix F). The items reflecting the most positive changes appeared clustered in category 2A (Family relation factors). The most positive was 2A-5 (Way family reacts to you) with $\underline{M} = +0.60$. This was followed by 2A-4 (Way you express feelings to family), 2A-6 (Way you react to family), and 3C-4 (Ability not to be hard on yourself), all with $\underline{M} = +0.50$. Item 2A-3 (Satisfaction from contacts with family) revealed $\underline{M} = +0.47$. Other changed items perceived as positive included 1B-4 (Importance of spiritual role), 2A-2 (Time spent with family), and 3A-2 (Ability to recognize a threat). The item with the most negative change was 8B-1 (Sexual satisfaction).

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PERCEIVED LIFE CHANGES IN ADULTS WITH ACQUIRED
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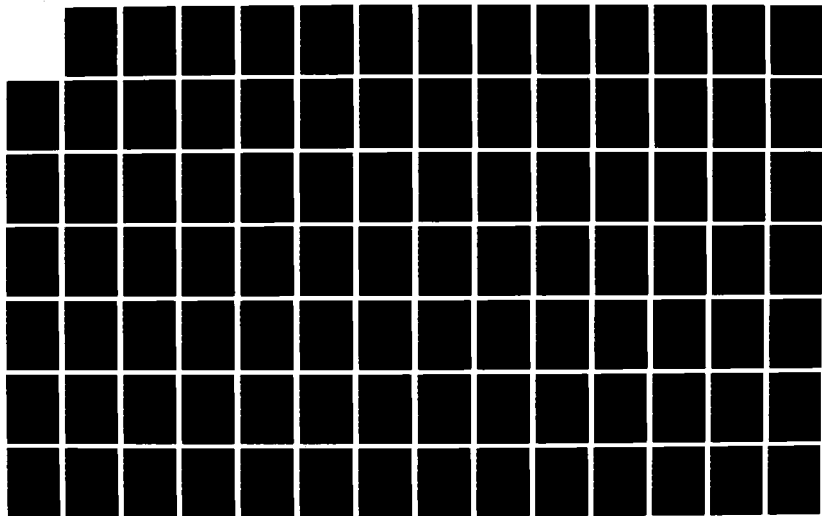
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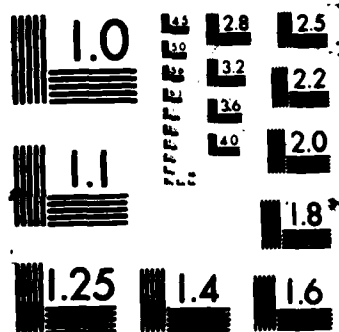
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irritation/itching) with $\underline{M} = -0.93$. That was followed by items 3A-7 (Irritation/inflammation of skin or mucous membranes) and 8B-2 (Sexual physical satisfaction), both with $\underline{M} = -0.77$. Changes in item 3A-5 (Susceptibility to infection) were perceived as negative with $\underline{M} = -0.73$. Category 8B had several other strong negative changes including 8B-3 (Physical ability to engage in sexual acts) with $\underline{M} = -0.70$, 8B-4 (Sexual emotional satisfaction) with $\underline{M} = -0.63$, and 8B-5 (Frequency of sexual activities) with $\underline{M} = -0.60$. Changes in item 8A-2 (How physically attractive you feel) were also quite negative with $\underline{M} = -0.63$. The P/N mean scores for the remaining 124 items fell between -0.53 and +0.27 (see Appendix F).

Importance of Change

The importance of changes was evaluated by having the participant assign a numerical value to the item of change on a scale of 1-100. Changes that were perceived as having no impact on the patient's life and items that did not change for the patient were assigned a value of "0". The mean score ($\underline{N} = 30$) for each item was calculated (see Appendix F), then these results were summarized by categories and subsystems (see Table 4). It is essential for the reviewer to comprehend the impact that the number of changes/responses for an item has on the IMP score. For example, a change item that would probably be considered

very important to a patient (such as pain or bleeding) could actually have a very low IMP score if only a few patients in the population experienced the change. Thus, for a few individuals that experienced a change like bleeding, the item might be rated with a high individual IMP score. The mean IMP score, however, which reflects the importance of the change for the entire population, would probably be very low. Both Table 4 and Appendix D list the mean IMP scores.

The mean importance (IMP) score for this population considering all changes from the DBSM Instrument was 29.1 (see Table 4). A look at the mean IMP scores for the subsystems reveals that the highest mean IMP score was held by the Sexual Subsystem ($\bar{M} = 44.6$). The Achievement and Affiliative Subsystems were next, with mean IMP scores of 36.5 and 35.7 respectively. The lowest mean IMP scores were held by the Eliminative Subsystem (12.2) and Ingestive Subsystem (16.9).

A closer examination reveals the mean IMP scores for the individual categories (Table 4). The category with the most important (highest scored) changes was 8B (Biopsychosocial determinants of sexual functioning) with $\bar{M} = 50.2$. Category 3B (Maintaining emotional stability) was also high with $\bar{M} = 49.7$. Changes in the "Importance of achieving" (1B) were considered quite important with a mean

IMP score of 42.7. The least important changes, as perceived by this population, were those in categories 5B (Genitourinary activity) with \bar{M} = 1.1 and 6A (Physical ability to obtain & process food) with \bar{M} = 7.2.

When the mean IMP scores for the 140 individual items of the DBSM Instrument are reviewed (see Appendix D), the item of change holding the highest score is item 3B-1 (Ability to be "old self") with \bar{M} = 61.5. Item 3A-5 (Infection susceptibility) was close with \bar{M} = 61.0. Items 8A-6 (Self-concept) and 8B-2 (Sexual satisfaction) followed with mean IMP scores of 59.5 and 59.1, respectively. Other items perceived as important by this population included 3B-2 (Ability to handle anger, fear, frustration) with \bar{M} = 58.8, 8A-2 (How physically attractive you feel) with \bar{M} = 55.9, and 2B-6 (Way you react to friends/relatives) with \bar{M} = 55.5. The least important items appear to be 6A-6 (Ability to get and eat prescribed foods), 6A-7 (Ability to tolerate receiving food/fluids by mouth), 5B-4 (Menstrual changes), and 5B-5 (Penile discharges), as the mean IMP score was zero (0) for each. This is somewhat misleading unless the reviewer is aware that this population experienced no changes in items 6A-6, 6A-7, or 5B-4. Only one participant identified a change in 5B-5. Items that were identified at changes, yet had a very low mean IMP score included most of the other items in category 5B: 5B-

2 (odor of urine/discharges) with \underline{M} = 0.8, 5B-3 (pain when urinating) with \underline{M} = 1.3, and 5B-1 (amount, frequency, color, or discomfort of urination) with \underline{M} = 2.3. Item 5A-2 (presence of blood in stool or emesis) received a low mean IMP score (2.7), however the item only had a 7% (2 participant) response rate. It is likely if this change occurred more frequently in the population, the IMP score would have been significantly higher. As with items 6A-6 and 6B-7, if the change occurred, the IMP score would likely be quite high.

CHAPTER 6

DISCUSSION

This chapter, like the preceding, will be presented in the order of the data collection process. A brief discussion of the participants (sample) will be followed by a discussion of the results pertaining to the DBSM Instrument. Last, a discussion of the results pertaining to the perceived life changes will be presented, including a summary of the reported impact of an AIDS diagnosis on each of the eight major subsystems.

The Participants

Although this sample of AIDS patients with Kaposi's Sarcoma (KS) was relatively small ($N = 30$), the demographic data (Table 1) closely parallels a larger sample of 200 patients with KS reported on from the Memorial Sloan Kettering Cancer Center (Safai, et al., 1985). The mean age, distribution of sex, race, and sexual orientation were essentially the same. It was acknowledged in the methods chapter that there might be some skewing of the sample of AIDS patients since they all were contacted at UCLA. The demographic data supports that concern. The education level of the population was higher than average, drawing from a sub-population of AIDS patients. It might be theorized that this sub-population (1) are inclined and motivated enough to actively seek care beyond their regular

physician, and (2) have adequate resources to pay for health care from a facility such as UCLA.

The demographic results describing "whom the diagnosis was shared with" and "sources of support" clearly indicate the selection of friends before family or relatives by this sample. This is not too surprising considering the predominance of the homosexual culture within this population. Many of these individuals have purposely kept their familial relationships limited due to fear of rejection or conflict over their chosen lifestyle (Clark, 1977).

The results indicating the incidence of utilizing health care workers as a major source of support were quite interesting. Physicians were cited as the second most common source of support for these patients. Also, despite minimal inpatient care since the time of diagnosis, a significant percentage felt nurses were a primary source of support (67%). It is quite possible that nurses could be viewed as a greater source of support if the outpatient population had greater access to them. Most participants identified access to a nurse occurring only as inpatients or during active involvement in a research protocol. Minimal nursing assessment and intervention appeared to be taking place outside of these two settings. After each of the formal interviews, the interviewer spent between 30 and 60 minutes with the participant discussing the shared

information. Almost all of the participants had questions or problems that fell within the realm of basic nursing management. Many, like nutrition, and pain management, were very familiar to the oncology clinical nurse specialist. The participants shared the observation that their physicians were so busy that they didn't seem to have time for these issues, and they really didn't know where else to turn.

This leads us to another observation from the demographic results. Several participants cited non-traditional care providers (metaphysicians, psychics) as sources of support. It is possible that this population is even more susceptible to unproven treatment methods than cancer patients. Today, most cancer patients have at least a potential treatment offered for their disease: surgery, radiation, or chemotherapy. Although AIDS patients are offered treatment for their KS, no proven treatment for the underlying disease (AIDS) is available within the traditional health care system. All health care providers need to be aware of this susceptibility so that they can at least help the patient choose sources/methods that will not endanger their lives further. Several patients share stories about "nutritionists" that advocated less than desirable diets.

Several patients that were utilizing a therapist for

support, were involved in such therapy prior to the AIDS diagnosis: "It was helpful before, but now it is invaluable". Clergy were cited as a support by about a third of the population. One participant told of his pursuit of Buddhism as a support. Weisman & Worden (1976) noted the existential searching of cancer patients as a characteristic reaction to the diagnosis of a life threatening illness. Holland & Tross (1985) noted the need to form new values and a new sense of self during the transitional stage of AIDS.

The range of "time since diagnosis" was considerable, and included several long term survivors (greater than 24 months). Although a correlation between time since diagnosis and perceived changes was not done, it is anticipated that this would be a significant variable. Returning for a moment to Johnson's Behavioral Systems Model, since the individual is always seeking a functional equilibrium, it makes sense to assume that the longer the person has to adapt to a change, the more likely he is to adapt. Additionally, as the disease progresses and symptoms change, a new balance must be sought. Nichols' (1985) Situational Distress Model for the psychosocial impact of AIDS identifies distinct stages of psychosocial response to the diagnosis related to time since diagnosis. The psychosocial characteristics of these stages would very

likely impact the "perceived life changes". Also, although not correlated, one might expect to find a difference in perceived disease impact between patients with/without a history of opportunistic infections in addition to KS.

The low incidence of hospitalizations since diagnosis reflects on both: this population's health status and the emphasis on outpatient care for this population. It has been observed that AIDS patients that have been diagnosed with KS, generally live longer and are less acutely ill than those diagnosed with opportunistic infections (CDC, 1987; Selwyn, 1986c).

The Instrument

Validity

The initial four member judge panel found the DBSM Instrument entirely valid with regard to its theoretical and operational base.

Comprehensiveness

The initial judge panel felt the DBSM was 100% comprehensive following minor additions. A second, separate judge panel, convened after data collection, found the same DBSM Instrument 97% comprehensive. This second judge panel made specific recommendations for four additional items to make the instrument truly comprehensive.

The first addition was an item noting change in their

"concern over society's attitude towards AIDS". Added by an early participant, 63% of the sample admitted their concern over this had changed since their diagnosis. Several of the participants shared how they had made elaborate arrangements to move/live outside the country if any of the quarantine threats actually materialized: "I will not be caged up!". It is noted that these interviews were conducted during some active political campaigning for such measures. Since many of these patients seemed to feel threatened by this issue, it should probably be added to the Aggressive/Protective System. It does have impact on the Affiliative Subsystem as well.

The second addition, "Ability to establish new relationships", was added by several patients. It is anticipated that this would change for anyone with a contagious, disfiguring, or socially unacceptable condition. This should be added to the Affiliative Subsystem, as it addresses relationships. The existing items cover changes in prior relationships but do not really address changes in the continuous process of establishing new relationships.

All judge panel members agreed on the need to address the specific "Use of alcohol, tobacco, or other recreational drugs for pleasure or relaxation purposes". Although "Reliance on medication to control emotional or men-

tal health" (4A-5) was included in the Dependency Subsystem, few patients associated alcohol or cigarette usage with this. Many patients added this change since the majority were attempting to improve their general health by decreasing such habits. It is suggested that this item be added to the Restorative Subsystem as stated above.

The last item recommended as an addition was one noting changes in "Feelings towards death/dying". It was felt that anyone facing a terminal, or even potentially terminal illness would likely experience changes in these feelings and attitudes. This population, (due to their youth), might be seriously thinking about death/dying for the first time. Several patients commented on how they had reevaluated their lives, changed their priorities, and made plans to accommodate their anticipated premature death. Although death/dying is certainly a sensitive issue, it is gradually becoming a more acceptable topic in our society. With this population, it would be almost insensitive to ignore an issue that most certainly has been on the minds of all of these patients. It should probably be addressed in the Aggressive-Protective Subsystem.

Reliability

The reliability of the DBSM Instrument was tested both by measuring internal consistency and a limited test-retest Pearson correlation. The results of the internal consis-

tency tests indicate that the instrument, overall, is highly reliable. Although the alpha scores decrease with further divisions of the instrument (into smaller units), the number of items within each analysis must be considered. Frequently there were only a few items (4-6) with only a few (1-3) responses to use in the analysis (see Appendix E). The Pearson (r) coefficients were generally quite high (See Appendix F). There were several low, and even negative, values that were noted throughout. As explained in the Results Chapter, the reasons for these values are unknown and may be a combination of several factors. The variability of the magnitude of the correlations might be due to the small test-retest sample size. Usually, n was only 6 or 7, meaning one deviation would have great impact. The negative direction of several item correlations could be related to item reliability, emotional impact of item, impact of completing entire DBSM prior to retest, or even fatigue.

Response to the Instrument

All participants responded positively to the interview, and all denied that it was too long or tedious. Several patients became teary eyed or cried during the interview, yet all stated that they had no regrets. As one patient stated, "I get emotional, but it's good to think about these things---it's important". Many stated that the

interview process helped them identify many positive changes that had occurred in their lives since their diagnosis of AIDS.

Perceived Life Changes

Keeping in mind the findings regarding the population and the DBSM Instrument, the focus will now be the perceived life changes that were reported. After a brief general discussion of the four aspects of changes (occurrence, direction, quality, and importance), more detailed findings will be discussed for each subsystem. This should summarize and link related findings for the reviewer.

Occurrence of Change

All eight subsystems, as expected, reflected perceived changes since diagnosis. The fact that the Sexual Subsystem experienced the highest occurrence of change is not surprising when one considers: (1) that sexual activity that was previously normal/routine for the patient would now endanger both the patient and his partner, and (2) that the predominant culture in this sample was homosexual.

The person with AIDS that engages in unprotected sexual activity takes two major risks: 1) Infecting a partner with HIV and 2) Contracting another illness that his impaired immune system is unable to protect him from.

Combined, they certainly promote a change of behavior. It is important to note that many who denied changes in some items of this subsystem reported altering their normal sexual behavior prior to their diagnosis, because they knew they were at risk.

Those involved in the homosexual culture place extreme importance on physical beauty and appearance. "Unlike the non-Gay man who is supposed to not notice other male bodies, the Gay man does notice other men and sees what is naturally beautiful about a body that is cared for with self-respect" (Clark, 1977, p. 53). The discoloring lesions of KS and cachectic appearance in the later stages of the disease obviously conflict with this value. Since the Sexual Subsystem included the dimension of "features and activities characteristic to the gender", the high occurrence of perceived changes is logical.

The higher occurrence of changes in the Achievement and Aggressive/Protective Subsystems was also expected. The physiological and psychological stressors associated with AIDS are well documented (Christ & Wiener, 1985; Dale & Avers, 1986; Ware, 1985). Changes in both ability and desire to achieve certain things are logical in the face of a debilitating and terminal illness. The developmental tasks of young adulthood include major achievement oriented activities: occupation, career, family, etc. (Christ &

Wiener, 1985). Wolcott (1986) notes that "life threatening illness in young adults often causes specific life cycle-related stresses". This is clearly evidenced in the Achievement Subsystem changes. The greater occurrence of changes in the Aggressive-Protective Subsystem seem obvious in the face of a life-threatening illness.

The low incidence of changes in the Eliminative Subsystem is probably influenced by the sample selection criteria of AIDS patients with KS, rather than those with opportunistic infections. AIDS patients experiencing certain infections (*Cryptosporidium*) certainly experience major eliminative pattern disruptions (CDC, 1982).

Direction of Change

The measure of direction of change for the various subsystems had only one overall change that was unexpected. The Affiliative Subsystem showed the second greatest increase in activity for this population. Concern over AIDS patients that are essentially alone and abandoned is very realistic (Christ & Wiener, 1985; Wolcott, 1986). With this population, however, there was an increase in affiliative activity. This may be partially explained by the outstanding and supportive network within the Los Angeles homosexual community. Yet, as will be discussed in detail later, this population also had an increase in familial af-

filiative activity.

Several of these values for the subsystems were very close to "0" indicating no overwhelming increase or decrease within the subsystems. The Sexual Subsystem was one notable exception with a substantial decrease in activity. The most probable reasons being fear of infection, loss of self esteem, fatigue, and the reorganization of priorities discussed previously. The Dependency Subsystem had a definite increase in activity which was not unexpected, considering the good health, youth, and subsequent independence of this population prior to their diagnosis of AIDS.

Quality of Change

Only one of the eight subsystems had an overall positive perception of the changes that occurred. The Affiliative Subsystem reflected positive changes in all three categories of relationships: familial, friends and relatives, and groups. As discussed above, this could not be anticipated for all patients based on the numbers of AIDS patients noted to be all alone, but it was very reassuring to see something so positive result from such a tragic illness. The perceived negative impact of the changes in the other seven subsystems is not unexpected. The specifics behind that negative perception should become

evident as the individual subsystems are discussed.

Importance of Change

All eight subsystems had some measure of importance assigned. The changes identified in the Sexual Subsystem were rated the most important by this population. Again, considering the perceived value and power of sexual attractiveness within the homosexual culture (Clark, 1977), the impact of physical appearance in common professions within the culture (Buckingham, 1986), and the importance of sexual exploration and partner selection for young adults (Christ & Wiener, 1985), these results are not surprising. A high importance score for the Achievement Subsystem reflect the fact that during young adulthood, the drive to achieve is very high. Disruption of the ability to pursue that drive would logically be perceived as quite important to this population. A relatively high importance score for the changes within the Affiliative Subsystem possibly reflects the fact that they, unlike most other changes, were perceived as positive. That alone could make them very important to this population.

Perceived Life Changes by Subsystem

The following discussion will attempt to summarize the multitude of results describing the perceived life changes reported by this population. Detailed results can be found in Appendix F.

Achievement Subsystem: Overall, this subsystem reflected a high occurrence of changes that were perceived as quite important to this population. Generally, these changes were perceived as a decrease in activity and were considered negative. The category reflecting the physical and mental ability to achieve (1A) had changes that were perceived as having a greater decrease in activity and more negative than the category noting the importance of achieving (1B). However, more changes were perceived with regard to the importance of achieving than with the ability to achieve and the changes regarding "importance of achieving" were considered more significant (having greater life impact) than the changes in "ability". This might be explained by the natural intensity of the achievement drive in this age group and also by the fact that the majority of this sample was actually still quite physically and mentally functional (based on Karnofsky's scale) and generally more educated, with a mean educational level of 16 years.

When individual items are considered, it should be noted that changes in item 1B-1 (Importance of planning/pursuing new ventures) reflected the second highest response rate in the instrument and had a high importance score. The JBSM theorizes that "the subsystems, and the system as a whole, has certain functional requirements that must be met through the individuals own efforts,

or through outside assistance, for each to grow, develop, and remain viable (Johnson, 1980, p. 212). Grubbs (1980) noted that when a basic drive is not adequately satisfied that one might: 1) increase the drive or 2) change the direction of the drive. In this situation, the patient's ability to master his environment is threatened, if not limited, by the physical impact of his illness. The strong Achievement drive, so characteristic of youth, can no longer be met. However, by changing the direction of this drive, to that of mastering "today" and "bodily functioning", rather than mastering "future events", might be a functional shift which might allow the system to regain balance. Interestingly, this item also drew a high response rate in Derdiarian's (1983) population of cancer patients.

This response also likely reflects a characteristic identified in the Situational Distress Model (Nichols, 1985; Selwyn, 1986d). Patients in the transitional stage of this model are dealing with social disruption and "need to form new values, a new sense of self, and a new community" (Nichols, 1985, p.766). Those moving on to the deficiency state (acceptance), are learning to accept the limitations imposed by the disease and identify new reasons for living. It appears that their achievement drive changes its focus from quantity to quality of life. This

is further supported by noting that ability to plan/pursue new ventures (1A-1) also reflects a high occurrence of change and that the change is considered very negative and very important. Changes regarding the completion of daily living activities, performance in usual social role, provision of financial security, and mental concentration, were all perceived as decreasing in ability and increasing in importance. Both the ability and importance of performing their usual spiritual role was perceived as increased, positive, and important, also possibly implying an increased focus on quality vs. quantity of life.

Affiliative Subsystem: This population perceived many changes in this subsystem, nearly all of which reflected an increase in activity. They were also considered very positive and were scored as being very important. This is the only subsystem in which the overall changes experienced were perceived as positive. The greatest amount of change, and increase in activity occurred in the category of familial relationships. Those changes were also considered the most positive and important among the group. Within the items addressing familial relationships, there was quite a focus on changes in the "way the family react to you"(2A-5). Again, the fact that the majority of the population was homosexual may partially explain these results. Many times homosexuals have put considerable dis-

tance between themselves and their families, both physically and emotionally (Clark, 1977; Christ & Wiener, 1985; Wolcott, 1986). This distancing is usually established prior to the diagnosis of AIDS due to their homosexual lifestyle. Being diagnosed with a terminal illness, reevaluating their priorities and goals, and possibly experiencing rejection within their culture or by a lover, might lead the patient back towards his family. This seems to be true, at least to a degree, whether or not the patient chooses to share the news of his diagnoses with family members. Recall that the demographic data indicated that only 67% of the population shared the diagnosis with relatives. Yet, 70-73% of them noted an increased closeness with family by recognizing an increased, positive, and significant (important) change in the way they react to one another (2A-5,6). Many of the participants shared their perception that their families were aware of their homosexual lifestyle prior to the diagnosis, even if it had never been openly discussed. Perhaps this helped alleviate the double trauma many families experience upon learning of a member's AIDS diagnosis (Christ & Wiener, 1985; Holland & Tross, 1985; Selwyn, 1986). This may help explain how the overwhelmingly positive changes in family relations occurred in this population. Many noted that they became much more open, expressing feelings to family more openly

than before (2A-4). Additionally, they felt this was a very positive and important change for them.

The perceived changes regarding friendships (2B) were also positive, although not as positive as those involving family relationships. Some participants considered their partner (lover) a "friend", others considered their partner "family", depending on the relationship. Item 2B-1 was difficult for participants regarding whether the "persons they felt close to" had increased or decreased. Usually, it seemed that the item had changed, but it both increased and decreased as they became closer to some friends and more distant from others. The I/D response was chosen based on whether, overall, they were close to more people or fewer people since their diagnosis was made. There was, overall, a slight increase in the amount of trust the participants had in their friends. As noted previously, "friends" in the homosexual culture take on a role of family for many. Feelings of alienation from families seem to make the friendship bond greater, resulting in the perceived increased importance of changes in these relationships.

The results noting changes in group relationships were less impressive. Most seemed to associate "group activities" with support groups. Few participants seemed very involved in clubs, etc.. There was much variety in

attitudes regarding support groups. Several of the long term survivors (greater than 24 months) indicated that support groups were very helpful for some people, at some points along the way, but not for others. It appeared that support group activities were perceived as being vital at some points and detrimental at others. Many shared that they had learned when to become involved or disengage, depending on what their mental and emotional status was.

Aggressive-Protective Subsystem: This subsystem had one of the highest percentage of changes occurring in this population. The category referring to the ability to maintain one's emotional stability (3B) had the greatest number of changes and these changes were perceived as the most important within the subsystem. Within this category, participants felt that their "ability to handle anger, fear, frustration" (3B-2) had changed 83% of the time and indicated that they perceived this ability to be increased, highly positive, and very important. They perceived that their "ability to be their 'old self'" had dramatically changed. This was reported as a major decrease and viewed by many as a negative change. Some participants stated that they liked themselves much better since the diagnosis, so they viewed this change as a positive one. Most felt an increased ability to give emotional support to others, possibly as a result of the depth of their own experiences and

fears. Most noted a somewhat decreased ability to keep their "emotions on an even keel"(3B-4), and felt this was a somewhat negative change.

Changes in Category 3A (Physical ability to protect) were considered, overall, the most negative of the three groups in the Aggressive-Protective Subsystem. The item that led this trend was "Irritation or inflammation of skin or mucous membranes" (3A-7), with one of the strongest scores for increasing activity and negative perception in the instrument. A physician visiting one of the UCLA AIDS clinics had commented that one of the greatest lessons to be learned from studying AIDS patients, was how closely immune system and skin status are linked. Item responses like this one, in conjunction with other highly scored items like "Skin irritations, itching" (5C-1), support such observations. Changes in "Infection susceptibility" also had a high occurrence rate (80%), reflecting a major increase and strong negativity and importance. Considering that this is what usually leads to the death of these patients, such a response is expected. Actually, the fact that 20% failed to perceive changes in their infection susceptibility is more interesting. Some of these patients either felt too well to believe that they were at increased risk for infection, or they just chose not to recognize that as reality (denial). The "ability to provide for or

care for oneself or others" (3A-3,4) was not noted as a change as frequently as expected. Nor was it rated as a very important change, overall. This might be influenced by the fact that nearly all of the participants has access to resources, of some sort, for support. This is not necessarily a characteristic of AIDS patients with KS but rather a reflection of the skewed population from which UCLA seems to draw many of its patients.

The greatest occurrence of change in Category 3C was "Ability not to be hard on yourself". This characteristic was noted as increased, highly positive and very important. In the search for optimum health behaviors, many of these patients stated that they did not push themselves as hard any more and that they were enjoying life much more as a result. Additionally, many felt their "ability to recognize a threat" (3C-6) had increased and indicated that this was a positive change of moderate importance to them. This is likely also related to the search for optimum health behaviors, which is one of the few things they can do to help themselves.

About one third of the patients perceived changes in their mental ability to carry on with responsibilities, to make decisions, and to concentrate (3C-1,2,3). These changes were perceived as decreased abilities with a negative impact on their lives. It was interesting that two of

the patients interviewed had, what appeared to be, definite slowing of the thought processes. Neither of the two acknowledged perception of this slowing. One had even been sent by his physician for neurological scans to determine a possible cause. Since there were no records to indicate whether or not they were always slow in responses, it was difficult to determine if this was actually a change for the individuals.

Dependency Subsystem: This subsystem had a significant occurrence of changes, with all the responses indicating an increase in the level of dependency. Although many of these changes were perceived as negative (physical dependency-4A), several were thought to be positive (emotional dependency-4B). All had a moderate level of importance. The items of change having the greatest occurrence and increase were both related to dependency on health professionals for care and information (4A-3; 4B-3). These were perceived as negative and were considered more important than any other Dependency Subsystem changes. Most of this young population probably had little or no contact with hospitals and health care professionals until the onset of their disease process. Also, virtually all the information they are getting is essentially bad news. It is not surprising that it is perceived in this way.

The use of medications for all purposes listed

(physical comfort, emotional health, prevention of illness, and nutritional supplements) (4A-4,5,6,7) had increased since diagnosis. These changes were perceived as negative, except for the nutritional supplements which were thought to be okay. The impact of these change were considered minimal. Of note was the item regarding changes in amount of physical touch needed to feel reassured. Half of the participants noted an increase in this item and felt it was a positive change of moderate importance. It seems natural that this would help decrease the feelings of being "dirty" or "leper-like" that has been referred to in the literature (Christ & Wiener, 1985). This would have important implications for care givers, especially in a situation where certain isolation precautions are required.

The items of change related to emotional dependency such as "relying on others for help, feelings of security" (4B-1,2) and the "need for religious support" were all increased significantly for almost half of the participants. Notably, these changes were primarily perceived as positive, and fairly important. This aspect of change may be tied to the existential searching acknowledge in terminally ill patients by Weisman & Worden (1976).

Eliminative Subsystem: The lowest incidence of change occurred within this subsystem. However, the changes occurring within the Integumentary Category (5C) were quite

significant. The Genitourinary and Gastrointestinal Categories actually reported minimal changes, with minimal impact. This is likely a reflection of the sample selection for AIDS patients with KS, rather than those with opportunistic infections. Although 12 of the KS patients did have a history of opportunistic infections as well, most had Candida or Pneumocystis Carini, which had minimal gastrointestinal and genitourinary impact. Half did have an increase in the "shape, form, color, content or amount of stool" (5A-4). This was further described by the patients as intermittent loose stools, which although overwhelmingly considered a negative change, actually had minimal impact on their lives. About half of those experiencing such changes in stool patterns had an increase in hemorrhoidal pain. This seems logical and was considered to be only minimally important by most. The changes in "odor of urine" (5B-2) were explained by new intake of vitamins, thus the virtual absence of impact (importance).

Skin irritations and itching (5C-1) were almost universal in occurrence, and had the greatest increase of any item of the instrument. This was also perceived as the most negative change noted in the instrument for this population. This tends to portray just how routine and bothersome this problem is in this population. It should also be noted that these changes were not usually in

reference to the specific KS lesions but rather to other dermatological manifestations. However, several patients did comment that they recalled having severe episodes of generalized pruritus right before new KS lesions appeared. The changes in sweating (5C-2) partially reflected the incidence of night sweats in this population. The data on this particular item of change may not fully depict the incidence as many patients experienced this symptom long before the actual diagnosis of AIDS, therefore it was not perceived as "a change since diagnosis". Nail changes (5C-6) are simply an extension of the dermatological manifestations discussed above, but are perceived as less important (having less impact on their lives). Puffiness, swelling, and edema are unfortunately expected with KS since this tumor invade the vasculature and often impedes the lymphatic system (Safai, et al., 1985). Actually the incidence and impact of this change were somewhat lower than what might be expected.

Ingestive Subsystem: Changes in this subsystem generally occurred with moderate frequency and had no real trends of showing an increase vs. decrease in activity. The changes were also neither generally positive or negative, nor were they perceived as having a significant impact. This may be deceiving in view of the fact the deteriorating nutritional status and cachexia is almost in-

evitable in the latter stages of AIDS (Gong, 1985). Changes did occur, most notably the "reason why you eat" (6C-2), indicating that these patients have an increased reason to eat, and eat well, following a diagnosis of AIDS. This item of change was considered somewhat positive and quite important. The "avoidance of certain foods" and "amount of usual food eaten" (6C-6,7) both changed for half the population. Many of the participants shared the fact that they had gone in search of nutritional counseling. Unfortunately, the use of registered dieticians for such counseling seems to be almost unheard of. Rather a variety of nutritionists, homeopathic and meta-physicains, even psychics were consulted. The concern over achieving the optimum nutritional balance to support and even "boost" the immune system was very real. This population had minimal decreases in the physical ability to obtain and process food (6A). Obtaining food, fortunately, was not a problem for most of the population. This probably was influenced by the identified skewing of the sample population by education and apparently, socioeconomic status. However, two patients had notable dental problems that impacted their ability to eat, and could not find a dentist that would treat them. Following the interview they were referred by the interviewer to a dentist at UCLA where they subsequently received care. This problem has been com-

mented on in the literature (Lang, et al., 1985) but continues to be a very real dilemma for those facing the challenge of finding a dentist that will treat AIDS patients.

Restorative Subsystem: Overall, this subsystem had a moderate amount of changes with no significant I/D or P/N trends and was rated moderately important. The greatest amount of changes occurred within the category "ability to relax" (7B). These changes were rated as increased and positive, although not by much. Also, the changes in this category were considered more important than the others: Amount and quality of sleep; Physiological and functional equilibrium. Several items in this category (7B) were considered significant by many. Specifically, "interest in restful leisure activities" and "time for leisure" (7B-3,6) were regarded as increase, positive, and fairly important. In contrast, the "ability to take part in active leisure activity" (7B-4) was notably decreased, negative, and was rated the most important change within this category. Considering the increased fatigue, noted to be a common symptom on an HIV infection, these results are not too surprising. It is proposed that the high negative impact of decreased ability to take part in active leisure activity, might be linked to the youth of the population. This relatively young group might normally be more active than an older population. This might also account for the

"great increase in interest in leisure activities". The increased time for leisure seemed to be related to the decreased work schedules of the majority of these patients.

The response from category A (Amount/quality of sleep) indicated an overall increase of the amount of sleep and a decrease in the quality of sleep. The change in the amount of sleep was considered slightly positive while the changes related to the quality of sleep were basically negative. The most negative of these changes was the decreased feeling of being rested after sleep (7A-5). This was also considered to be the most important change in this category, correlating with the frequently noted complaints of severe fatigue, and general malaise (Gong, 1985, Lang, et al., 1985).

Although the changes in category C (Physiological and functional equilibrium were overwhelmingly negative, they seemed to have only a moderate impact on this population. The most negative change noted was that of an alteration in "rate/depth of breathing" (7C-1) and likewise, "feeling that you have enough air" (7C-2). Apparently this population did not feel too threatened by this change as the importance score was only moderate (25-26). Another notably negative change was "sensations/tingling in toes, fingers, muscles" (7C-3). This may be indicative of early neurological involvement, noted to be very common with this

infection (Levy, et al., 1985; Wolcott, et al., 1985). Interestingly, although almost half noted an increase in "time required for recovery from colds/infections" (7C-5), less than one quarter noted an increase in the time required for cuts/lesions to heal (7C-6). This, despite the documented impact on the integumentary system (Category 5C).

Sexual Subsystem: This subsystem overall, reflected the most change, the greatest decrease in activity, the most negatively perceived changes, and the most important changes. Category B (Biopsychosocial determinants of sexual functioning) reflected the greatest changes in all of these. Considering the fact that AIDS patients know they are carriers of HIV and therefore contagious to partners during unprotected sexual activity, this is not too surprising. A number of participants stated that they had made many of these changes prior to diagnosis since they knew they might be at risk. Those participants would have reflected fewer changes since the behavior changed prior to diagnosis. The item reflecting the greatest change was 8B-5 (frequency of sexual activities), although this was closely followed by changes in the methods of satisfying sexual desire (8B-6) and sexual physical satisfaction (8B-2). This response agreed with that predicted, based on the review of the literature. The most negatively

perceived and important of these changes was that of sexual physical satisfaction.

The only change within this category that was increased and positive was the "desire to find/keep an intimate relationship" (8B-8). Patients often elaborated on how this suddenly had much more meaning and more importance than ever before. This is understandable if one considers the classic homosexual culture (Clark, 1977), which seemed to advocate numerous short, intense, relationships rather than lengthy relationships with emotional ties. It has been noted that with the epidemic of AIDS, that characteristic might be changing (CDC, 1985; Riesenbergr, 1986).

Changes in category A (Physical activities characteristic of gender) were also mostly negatively perceived. The greatest number of changes occurred in the item reflecting "how physically attractive you feel" (8A-2). This likely reflects the fact that all these patients had Kaposi's lesions, as well as a diagnosis of AIDS. This change was also reflected by an increase in their desire to make themselves look attractive (8A-3). This was significantly accompanied by a strong response regarding ability to keep up with activities that made them feel good about their maleness (keeping up with fashion, going to gym, etc.). Over half reported this ability had decreased and found the change quite negative (8A-1). The most

negatively perceived change within this group was that of one's "ability to perform in usual gender role (male homosexual). Interestingly though, this was not considered the most important change in this group. Rather, decrease in "self concept" (8A-6) was the most important change for this group. This may reflect many things, including the change in life priorities, a realization of one's own mortality, and reassessment of one's relationships, referred to as existential searching by Weisman & Worden (1976) as a frequent experience for terminally ill patients.

It was interesting to note that few participants reported any change in their "comfort with sexual identity" (8A-7). Some that did have a change, indicated that they were more positive about it than before. It was anticipated that many would have changes in this item in light of the "internalized homophobia" referred to in the literature (Christ & Wiener, 1985; Wolcott, et al., 1985). The fact that most of these patients came from Southern California communities, in which their homosexual or bisexual lifestyle might be more supported than in other areas of the country, may help to explain this response.

CHAPTER 7

CONCLUSION

At the outset of this study, two objectives were specified: (1) to describe perceived life changes occurring in adult AIDS patients with Kaposi's sarcoma in terms of occurrence, direction, quality, and importance; (2) to evaluate the DBSM Instrument in the adult AIDS patient population for validity, reliability, and comprehensiveness. A summary of the achievement of these objectives, followed by the implications of findings, will be presented in this chapter.

Summary

The data retrieved provided a description of the life changes perceived by a group of adult AIDS patients with Kaposi's Sarcoma ($N = 30$). These changes were identified by the sample in terms of occurrence, direction (increased/decreased), quality (positive/negative), and importance (scale 1-100). The instrument utilized in collecting this data (DBSM Instrument) was found to be valid, with regard to its theoretical and operational base, and comprehensive (>97%) by two separate judge panels. A judge panel review of the items added by the subjects, did not find that any additional categories were necessary. The instrument was also found to be reliable by measures of internal consistency and a limited test-retest Pearson

product-moment correlation.

Implications

The implications of this study are many. Due to the large quantity of material, each specific subsystem will not be discussed. Rather, several subsystems will be utilized in guiding the reader towards some of the theoretical, practical, educational, and research implications.

Theoretical Implications

The evaluation of the DBSM Instrument, particularly the measure of comprehensiveness, provides strong support for the Johnson Behavioral System Model Theory. The evaluation of the actual instrument's validity and reliability provides strong support for the use of the DBSM Instrument, at least with this population. A previous evaluation of the DBSM Instrument in general oncology patients provided similar support (Derdarian & Forsythe, 1983). The empirical support of both the theory and derived instrument establishes a precedent for continued use of both, in nursing practice and research.

Further use and testing of both the JBSM and DBSM Instrument are recommended. Utilizing other populations of AIDS patients, that would alleviate some of the limitations noted in this study, would be especially helpful.

Specifically, the study of AIDS patients without Kaposi's Sarcoma, AIDS patients from a greater variety of educational and socioeconomic levels, patients that come from a heterosexual culture, female patients, and those with other sources of HIV infection, would strengthen these findings.

The potential theoretical implications for future nursing studies include the provision of a sound, systematic, and comprehensive basis for nursing practice and research, as well as a comprehensive and specific instrument to use in the process. In a time of intense struggles and searching within the nursing profession for just such structure, this could provide a major pathway for the future of nursing.

Implications for Practice

There are actually implications for practice that can be derived from each objective achieved. The first objective resulted in a description of the perceived life changes of patients diagnosed with AIDS and Kaposi's Sarcoma. The description of symptoms and feelings experienced by this population should provide direction and focus for health care professionals striving to provide comprehensive care for these patients. This information should help the provider be more sensitive to both specific changes experienced by these patients and to the

impact of these changes on their lives.

An example of applying such sensitivity might be: increasing the provider's awareness of the impact of the patient's decreased ability to express himself sexually. The preponderance of changes in self concept, feelings of attractiveness, and in ability and desire to make oneself look good, should guide the caretaker towards assisting the patient with these needs. Increased attention to and possibly assistance with grooming, dressing, shopping, and make-up, become obviously very important in the care and support of this population. Many similarities might be drawn between this population and others suffering from debilitating or disfiguring illnesses. The emphasis on assisting mastectomy patients with obtaining prostheses, and wigs for patients receiving certain chemotherapy, are comparable therapies. Along these same lines, making sexual counseling available to these patients is just as important as providing it to any patient that must alter their sexual practices. Like the vulvectomy, bilateral orchiectomy, and even ostomy patients, these patients need and deserve counseling about their concerns and about alternative means of sexual expression.

Additionally, despite concerns about homophobia, and possible relationship between the source of a patient's HIV infection and homosexual culture, the patient might

still feel most comfortable within that culture (as did most of this this sample). Access to friends and activities within their culture should be promoted and encouraged. This would be comparable to providing support for immediate family members and attempts to meet other cultural needs and concerns.

Many other implications for practice can be found within the extensive descriptive information retrieved. Reviewing information from the data sheet and noting the wide variety of resources these patients tapped into, should alert care providers to several things. First, these patients should all be provided access to good, legitimate, nutritional counseling. Second, all care providers should be alert to the frequent utilization of nontraditional therapies with this population. Reviewing the documented experiences of cancer patients with many nontraditional therapies, one might advocate exploring this possibility in a non-judgemental, open manner. Therapies that seem to be essentially harmless should not be discouraged. Those which truly threaten the safety and welfare of the patient, should be discouraged by explaining the threat to the patient and hopefully offering the patient alternatives that would be less harmful (Holland, 1982; Howard-Ruben & Miller, 1984). This search for alternatives, or "something rather than nothing" provides

these patients with a method of "reasserting personal control over the situation and, at the same time, offers an antidote for the sense of helplessness" (Holland, 1982, p.11).

Another implication for practice that could be derived from the data for this population is the attention needed to the dermatological manifestations of this disease. Items related to these signs and symptoms received the most attention of any within the DBSM Instrument. In a situation where palliative care becomes paramount, this issue, like pain control and hydration, deserves more attention. Certainly problems like intense pruritus, burning, and dryness of the skin, can be major factors influencing the quality of life. Based on the importance ratings allotted by this sample, these symptoms deserve more of our attention and better interventions.

Last, this data helps the care provider identify several possible interventions that may assist the AIDS patient in coping more effectively with the diagnosis. In addition to encouraging support of friends and family, the provider can see that additional spiritual resources are made available, as desired by the patient. Attention to a patient's decreasing "ability to achieve" might be very appropriate. Programs like "Make Today Count", sponsored by the American Cancer Society, might help the patient

refocus his achievement drive on smaller, more reasonable goals, thus regaining a sense of achievement. Also, although difficult, helping patients focus on positive changes that have occurred since diagnosis may help prevent feelings of depression and total negativism. Surprisingly, all of the patients in this sample identified some positive changes that occurred since their diagnosis. Examples included positive changes in specific relationships (familial and other), increased time for leisure, and new perspectives on life. Remarkably, several indicated that the entire experience had been the best and most valuable of their life. "It's a shame we have to go through something like this to realize what life is all about."

The second objective, reflecting the validity, comprehensiveness, and reliability of the DBSM Instrument, offers current and future care providers with an excellent tool for further study and treatment of this population. Although admittedly time consuming, this interview appeared to accurately identify and evaluate both positive and negative changes impacting the lives of these patients. Additionally, and most importantly, application of the JBSM theories allows the interviewer to quickly identify problems and plan interventions for the patient (Grubbs, 1980). Also, the positive changes identified by

the patient could be utilized in planning his future care and identifying potential resources for support. In times of increasing concern over quality and comprehensiveness of care, this instrument could be invaluable.

Implications for Education

Unfortunately, the numbers of people in our society that will need health care due to AIDS is skyrocketing. During 1991 an estimated 144,000 AIDS patients will require care in the United States alone (Morgan & Curran, 1986). The corresponding need for education of current and future health care providers cannot be ignored. Research findings, like those presented herein, will give care providers an accurate description of the perceived life changes and problems of the this new challenging patient population.

In addition to teaching practical application of the findings, an important opportunity for teaching a standard, comprehensive method of assessment and intervention exists within the method of this study. Based on the results of the DBSM Instrument evaluation, this instrument, pending further evaluation, could be considered a prototype for an ideal assessment tool for nursing practice. Exposure to such an instrument during a nurses basic clinical education would provide, what appears to be, a sound theoretical framework upon which to

build a practice.

Implications for Research

Again, research implications can be derived from each of the objectives achieved. The descriptive data provides an initial data bank of documented perceived life changes in a population of AIDS patients. This data will need to be supported and added to by subsequent studies of similar and different AIDS populations. As noted under Theoretical Implications, other types of AIDS patients (without KS, heterosexual, female, different educational levels, etc.) require similar study. A particular variable that warrants further study is that of: time since diagnosis. The impact of time on one's ability to seek and establish a new equilibrium (JBSM) and on the proposed trajectory through the "Situational Distress Model of Crisis" (Nichols, 1985) warrants further evaluation and study. As an initial descriptive study with a limited sample size, this variable was only noted. A better understanding of this variable would accord care providers with a better understanding of the probable timing of specific changes and problems.

Other research implications can be derived from the descriptive data. Having identified the high occurrence, extreme negativity, and importance, assigned to increasing dermatological manifestations, how should we intervene?

What works best for the pruritus? Systemically? Topically? Do starched vs. unstarched sheets make a difference? How can the complaints of tingling, burning pain, or numbness best be managed to maintain some quality of life? Will the same approaches used for anorexia and cachexia in cancer patients help these patients? Will something else work better? Will AIDS patients that do not have, or will not use, the support structures established by the homosexual community have different perceived life changes following a diagnosis of AIDS? The list of questions is literally, endless.

The research implications derived from the second objective are actually even more extensive. The DBSM Instrument has now been empirically supported as a valid, comprehensive, and reliable tool in two studies. Both studies involved patients with oncological conditions, however, current similar studies utilizing cardiac patients and diabetics are indicating comparable findings (Derdiarian, 1987). The establishment of such an instrument opens the doors for extensive, theoretically based research on many patient populations. Most importantly, this theoretical framework (JBSM) was derived from and aligned to the basic practice of nursing. "Nursing is (or could be) the force that supplies assistance both at the time of occurrence {of an imbalance in the subsystem} and

at other times to prevent such occurrences." (Johnson, 1980, p.209). Thus, it speaks to the needs and goals of the nursing care provider. Also, Johnson developed a framework for nursing research within her model as noted in her description of nursing's research task: "to identify and explain the behavioral system disorders which arise in connection with illness, and to develop the rationale for and means of management" (Johnson, 1968). The DBSM Instrument appears to provide the nurse researcher with the first step of achieving that goal.

REFERENCES

- American Nurses' Association. (1980). Nursing: A social policy statement. Kansas City, MO: Author.
- Auger, J. R. (1976). Behavioral systems and nursing. Englewood Cliffs, NJ: Prentice-Hall.
- Batten, C., & Tabor, R. (1983). Nursing the patient with AIDS. Canadian Nurse, 79, 19-22.
- Buckingham, S. (1986, January). Psychosocial components of caring for the AIDS patient and family. Paper presented during Nursing Grand Rounds, sponsored by the Neuropsychiatric Institute, University of California, Los Angeles.
- Centers for Disease Control. (1982). Cryptosporidiosis: Assessment of chemotherapy of males with acquired immunodeficiency syndrome (AIDS). Morbidity and Mortality Weekly Report, 31, 589-592.
- Centers for Disease Control. (1985). Self reported behavioral changes among homosexual and bisexual men--San Francisco. Morbidity and Mortality Weekly Report, 34(40), 613-615.
- Centers for Disease Control. (1986a). Tuberculosis--United States, 1985--and the possible impact of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus infection. Morbidity and Mortality Weekly Report, 35(5), 74-75.
- Centers for Disease Control. (1986b). Update: Acquired immunodeficiency syndrome--United States. Morbidity and Mortality Weekly Report, 35(49), 757-766.
- Centers for Disease Control. (1987, March 16). AIDS weekly surveillance report. United States AIDS Program, Center for Infectious Diseases (p.1). Atlanta, GA: Author.
- Chin, R. (1961). The utility of system models and develop mental models for practitioners. In W. Bennis, K. Benne, & R. Chin (Eds.), The planning of change: Readings in the applied behavioral sciences (pp. 297-312). New York: Holt, Rhinehart, & Winston.

- Christ, G. H., & Wiener, L. S. (1985). Psychosocial Issues in AIDS. In V. T. DeVita Jr., S. Hellman, & S. A. Rosenberg (Eds.), AIDS: Etiology, diagnosis, treatment, and prevention (pp. 275-296). Philadelphia: Lippincott.
- Clark, D. (1977). Loving someone gay. New York: Signet.
- Coleman, D. A. (1986, July). How to care for an AIDS patient. RN, 16-21.
- Coppola, V., & Zabarsky, M. (1983, August 8). Coming out of the closet. Newsweek, p. 34.
- Cuff, M. E. (1985). Caring for the AIDS patient. In V. Gong (Ed.), Understanding AIDS, (pp. 149-165). New Brunswick, NJ: Rutgers University Press.
- Dale, C., & Avers, J. (Eds.). (1986). AIDS reference guide for medical professionals (2nd ed.). Los Angeles: Regents of the University of California.
- Damus, K. (1980). An application of the Johnson behavioral system model for nursing practice. In J. P. Riehl & C. Roy (Eds.), Conceptual models for nursing practice (pp. 274-289). New York: Appleton-Century-Crofts.
- Derdarian, A. (1983). An instrument for theory and research development using the behavioral systems model for nursing: The cancer patient, Part I. Nursing Research, 32(4), 196-201.
- Derdarian, A., & Forsythe, A. (1983). An instrument for theory and research development using the behavioral system model for nursing: The cancer patient, Part II. Nursing Research, 32(5), 260-266.
- Fawcett, J. (1985). Analysis and evaluation of conceptual models. Philadelphia: F. A. Davis.
- Forstein, M. (1984). The psychosocial impact of the acquired immunodeficiency syndrome. Seminars in Oncology, 11(1), 77-82.
- Freeman, W. R., Lerner, C. W., Mines, J. A., Lash, R. S., Starr, M. B., Nadel, A. J., & Tapper, M. L. (1983). A prospective study of ophthalmologic findings in acquired immune deficiency syndrome. Abstracts of the 23rd ICAAC (Abstract 224). American Society of Microbiology, Washington D.C..

- Furstenberg, A. & Olsen, M. (1984, Summer). Social work and AIDS. Social Work in Health Care, 9(4).
- Gong, V. (Ed.). (1985). Understanding AIDS. New Brunswick, NJ: Rutgers University Press.
- Groopman, J. E. (1983). Kaposi's sarcoma and other neoplasms. In M. S. Gottlieb (Moderator), The acquired immunodeficiency syndrome. Annals of Internal Medicine, 99, 208-210.
- Grubbs, J. (1980). An interpretation of the Johnson behavioral system model for nursing practice. In J. Riehl & C. Roy (Eds.), Conceptual models for nursing practice (2nd ed.), (pp. 217-249). New York: Appleton-Century-Crofts.
- Holland, J. C. (1982). Why patients seek unproven cancer remedies: A psychological perspective. Ca-A Cancer Journal for Clinicians, 32 (1), 10-14.
- Holland, J. C., & Tross, S. (1985). The psychosocial and neuropsychiatric sequelae of the acquired immunodeficiency syndrome and related disorders. Annals of Internal Medicine, 103, 760-764.
- Howard-Ruben, J. & Miller, N.J. (1984). Unproven methods of cancer management Part II: Current trends and implications for patient care. Oncology Nursing Forum, 11(1), 67-73.
- Johnson, D. E. (1959). A philosophy of nursing. Nursing Outlook, 7, 198-200.
- Johnson, D. E. (1968, April). One conceptual model of nursing. Paper presented at Vanderbilt University, Nashville, TN.
- Johnson, D. E. (1980). The behavioral system model for nursing. In J. P. Riehl & C. Roy (Eds.), Conceptual models for nursing practice (pp. 207-216). New York: Appleton-Century-Crofts.
- Kovacs J. A., & Masur, H. (1985). Opportunistic infections. In J. I. Gallin & A. S. Fauci (Eds.), Advances in host defense mechanisms, Volume 5. New York, Raven Press.
- Lang, J. M., Spiegel, J., & Strigle, S. M. (1985). Living with AIDS: A self care manual. Los Angeles: AIDS Project, Los Angeles (APLA).

- Lehman, V., & Russell, N. (1985). Psychological and social issues of AIDS and strategies for survival. In V. Gong (Ed.), Understanding AIDS (pp. 175-189). New Brunswick, NJ: Rutgers University Press.
- Levy, R., Bredesen, D., & Rosenblum, M. (1985). Neurological manifestations of the acquired immunodeficiency syndrome (AIDS): Experience at UCSF and review of the literature. Journal of Neurosurgery, 62, 475-495.
- Malasanos, L., Barkauskas, V., Moss, M., & Stoltenberg-Allen, K. (Eds.) (1977). Health Assessment. St. Louis: C. V. Mosby.
- Malyon, A. K., & Pinka, A. T. (1983). Acquired immune deficiency syndrome: A challenge to psychology. The Professional Psychologist, 7, 1-11.
- Morgan, W. M., & Curran, J. W. (1986). Acquired immunodeficiency syndrome: Current and future trends. Public Health Reports, 101(5), 459-465.
- Murdaugh, C. (1986). Critique of the study design. In L. F. Phillips (Ed.), A clinician's guide to the critique and utilization of nursing research (pp. 203-248). Norwalk, CT: Appleton-Century-Crofts.
- Murray, T. H. (1985). Ethical issues in AIDS. In V. Gong (Ed.), Understanding AIDS (pp. 122-134). New Brunswick, NJ: Rutgers University Press.
- Namir, S. (1986, February). AIDS: Acquired immune deficiency syndrome psychosocial effects. UCLA School of Public Health Community Affairs & Development Committee (Sponsor), Public Forum, Los Angeles, CA.
- Nichols, S. E. (1985). Psychosocial reactions of persons with the acquired immunodeficiency syndrome. Annals of Internal Medicine, 103, 765-767.
- Newmark, D. Al (1984, July). Review of a support group for patients with AIDS. Topics in Clinical Nursing, 38-44.
- Perry, S W., & Tross, S. (1984). Psychiatric problems of AIDS inpatients at the New York Hospital: Preliminary report. Public Health Reports, 99, 200-205.
- Polit, D., & Hungler, B. (1983). Nursing research: Principles and methods (2nd ed.). Philadelphia: J. B. Lippencott.

- Public Health Service (1986). Plan for the prevention and control of AIDS and the AIDS virus. Report of the Coolfont Planning Conference. Meeting conducted at the Coolfont Conference Center in Berkeley Springs, WV, June 4-6.
- Rapoport, A. (1968). Foreward in W. Buckley (Ed.), Modern systems research for the behavioral scientist (p. xvii). Chicago: Aldine.
- Reichert, C. M., O'Leary, T. J., Levins, D. L., Simrell, C. R., & Macher, A. M. (1983). Autopsy pathology in the acquired immunodeficiency syndrome. American Journal of Pathology, 112, 357-382.
- Riesenberg, D. E. (1986). AIDS prompted behavior changes reported. Journal of the American Medical Association, 225(12), 176-177.
- Royal College of Nursing. (1986). Nursing guidelines on the management of patients in a hospital and the community suffering from AIDS. London: Author.
- Rubinou, D. (1984, July). The psychosocial impact of AIDS. Topics in Clinical Nursing, 26-30.
- Ryan, L. J. (1984, July). AIDS: A threat to shysical and psychological integrity. Topics in Clinical Nursing, 19-25.
- Safai, B., Johnson, K. G., Myskowski, P. L., Koziner, B., Yang, S. Y., Cunningham-Rundles, S., Godbold, J. H., & Dupont, B. (1985). The natural history of Kaposi's sarcoma in the acquired immunodeficiency syndrome. Annals of Internal Medicine, 103, 744-750.
- Schietinger, H. (1986, September). A home care plan for AIDS. American Journal of Nursing, 1021-1028.
- Selwyn, P. A. (1986c). AIDS: What is now known: III. Clinical aspects. Hospital Practice, 21(9), 119-153.
- Selwyn, P. A. (1986d). AIDS: What is now known: IV. Psychosocial aspects, treatment prospects. Hospital Practice, 21(10), 125-164.
- Viele, C. S., Dodd, M. J., & Morrison, C. (1984). Caring for acquired immune deficiency syndrome patients. Oncology Nursing Forum, 11,(3), 56-60.

- Ware, J. E. (1984). Conceptualizing disease impact and treatment outcomes. Cancer, 53(Suppl. May), 2316-2323.
- Weisman, A. D. (1979). A model for psychosocial phasing in cancer. General Hospital Psychiatry, 1, 187-195.
- Weisman, A. D. & Worden, J. W. (1976). The existential plight in cancer: Significance of the first 100 days. International Journal of Psychiatry Medicine, 7, 1-15.
- Weiss, K. (1983). AIDS turmoil in the medical profession. The New Physician, 32(6), 14,16.
- Wellish, D. K. (1985). UCLA psychological study of AIDS. Frontiers in Radiation Therapy Oncology, 19, 155-158.
- Wolcott, D. (1986). Psychosocial aspects of the acquired immune deficiency syndrome and the primary care physician. Annals of Allergy, 57, 95-102.
- Wolcott, D. L., Fawzy, F. I., & Pasnau, R. O. (1985). Acquired immune deficiency syndrome (AIDS) and consultation-liason psychiatry. General Hospital Psychiatry, 7, 280-292.

APPENDIX A

Adjustments to DBSM Instrument for AIDS Population

ALTERATIONS IN THE
DERDIARIAN BEHAVIORAL SUBSYSTEM MODEL INSTRUMENT
WHEN UTILIZED FOR AIDS PATIENTS

PAGE 1A:

CHANGE: Ability to perform in your usual social role
(such as husband/wife, mother/father,
homemaker/breadwinner)

TO: Ability to perform in your social role (such as
spouse/lover, mother/father, son/daughter,
homemaker/breadwinner)

Rationale: According to the Center for Disease Control
(CDC), 1984, 72% of AIDS patients are homosexual or
bisexual. I believe that the terms spouse/lover
would be easier to identify with than husband/wife.
Since that majority of these patients are young (69%
<40 years old)[3] they are frequently still acting
in the role of son/daughter (possibly more than
mother/father).

PAGE 3A:

ADD TO CHANGES: susceptibility to infection

Rationale: Lack of a functional, intact immune system
is a well known and well documented result of AIDS.
Patients are advised regarding their lack of immune
system defenses and of the constant threat of
infection. [1,3,5,14] In practically all AIDS
patients, opportunistic infections are the ultimate
cause of death [1].

PAGE 5B:

ADD BEFORE EACH OF THE FOLLOWING "CHANGES":

FEMALES:

menstrual flow or cycle (length, regularity, color,
amount)

MALES:

usual penile discharges (amount, type, color,
frequency)

Rationale: Feel this would clarify the type of informa-
tion requested of each sex. Expect that some men
would not want to be asked about their menstrual
flow etc.

PAGE 6A:

WOULD PROPOSE MOVING: ability to get or eat prescribed foods from Page 6B to 6A.

Rationale: It seems that this aspect of ingestion is more closely related to the "ability to obtain" than the "ability to assimilate" food.

PAGE 6B:

CHANGE: ability to get or eat favorite foods

TO: desire to eat favorite foods

Rationale: Feel that this was probably a typographical error as "desire to eat" is more in keeping with the "assimilation category and is the title utilized in the item analysis published (Derdarian, 1982).

PAGE 6C:

DELETE: ability to get or eat prescribed foods

Rationale: Change in this item is evaluated previously. Do not think this would significantly impact the gratification obtained in eating.

ADD TO CHANGES: who you share your mealtimes with

Rationale: Due to the social stigma attached to these patients and the fear of communicability [4,5,6,7,8,10,11], AIDS patients would probably often lose the psychosocial gratification achieved by sharing mealtimes with friends and family members. I believe this factor would reflect change and significant impact in the AIDS population.

Rationale: Same as above regarding ADDED CHANGE on 6C.

PAGE 8A:

CHANGE: ability to perform in usual sexual roles (such as husband or wife, male or female)

TO: ability to perform in usual sexual roles (such as spouse/lover, male or female)

Rationale: 72% of AIDS patients are homosexual or bisexual (CDC) and therefore feel that the revised change would be more meaningful

ADD TO CHANGES: Comfort with sexual identity
(male/female, heterosexual/homosexual/bisexual)

Rationale: This is aimed at addressing a concern of many AIDS patients, particularly the 72% that are homosexual or bisexual. Many homosexual patients are forced to confront the issue of their homosexuality openly, due to the diagnosis of AIDS [3,11,13]. In a 1982 study by Coppola and Zabarosky, 4 out of 5 urban homosexuals had not told their families of their homosexuality. Since the establishment of male homosexual sexual practices as a source of contracting AIDS, patients who have contracted AIDS this way must face the probability that they caused their own fate. Many homosexuals find themselves dealing again with self-hate, questioning their sexual identity and orientation. [5,11,13] I feel that this change represents a source of great stress to many of these patients, and therefore should be assessed.

DELETE FROM "CHANGES": (1) breast size
(2) size of testes

Rationale: Nothing in the literature indicates that AIDS patients face changes in either of these two categories.

PAGE 8B:

ADD TO CHANGES: methods of satisfying sexual desire/needs

Rationale: Following diagnosis of AIDS, patients are advised to alter or abstain from sexual intercourse as it is a significant source of infection for the patient (opportunistic infections) and for the partner (AIDS). This usually requires a change in the patient's normal method of satisfying sexual needs (relieving sexual tension); most patients find this extremely stressful. [3,4,11,14]

ALTERATIONS RECOMMENDED BY JUDGE PANEL:

6A - ADD TO CHANGES: ability to tolerate receiving food and fluids in the normal manner (by mouth)

Rationale: Many patients require high protein tube feedings as treatment for the profound body wasting that occurs in the later stages of this illness.

APPENDIX B
DBSM Instrument

PERSONAL DATA

Please fill in the blank or circle the most appropriate responses:

1. Age: _____
2. Sex: a. Male b. Female
3. Race: a. Caucasian b. Black c. Oriental d. Hispanic
 e. Am. Indian f. Other: _____
4. Years of education completed (Highest level):
 a. Elementary d. College 1-2 yrs. g. Master's degree
 b. Junior High e. College graduate h. PhD degree
 c. High School f. Post graduate courses i. Post Doctoral
5. Length of time since diagnosed with AIDS (months): _____
6. Since diagnosis with AIDS, you have had to deal with:
 a. Kaposi's sarcoma (skin lesions)
 b. Infections (pneumonia, candida, ecc.)
 c. Both Kaposi's sarcoma and infections
7. Your most probable source of infections with the AIDS virus was:
 a. Sexual activity with opposite sex
 b. Sexual activity with same sex
 c. Intravenous drug usage
 d. Blood/blood product transfusion
 e. Unknown
 f. Other: _____
8. You think of yourself as a person who is:
 a. Meterosexual b. Homosexual c. Bisexual
9. This hospitalization represents the _____ time you've been hospital-
ized since you were diagnosed with AIDS.
 a. first c. third e. greater than
 b. second d. fourth the fourth
10. Have you shared your diagnosis with your relatives? Yes No
 " " " " " with your friends? Yes No
11. Please circle the types of support that you are currently utilizing to
help you deal with the impact of this illness:
 a. Family c. Spouse/Lover e. Therapist g. Nurse
 b. Friends d. Support Groups f. Physician h. Clergy
 i. Other: _____
11. Do you have someone to rely on for assistance at home? a. YES b. NO

#1A

NOTED CHANGES

	CIRCLE		CIRCLE Positive (P) or Negative (N)	LIST Importance on a Scale (1-100)
	Increase (I) or Decrease (D)			
1. <u>Ability to plan and pursue new ventures or projects (education, career advancement, travel)</u>	I	D	P N	_____
2. <u>Ability to complete daily living activities</u>	I	D	P N	_____
3. <u>Ability to perform in your usual social role (such as spouse/lover, mother/father, son/daughter, homemaker/breadwinner)</u>	I	D	P N	_____
4. <u>Ability to perform in your usual spiritual or religious role (such as praying, attending church)</u>	I	D	P N	_____
5. <u>Ability to provide financial security for self or family (function in job, buy insurance, plan investments)</u>	I	D	P N	_____
6. <u>Ability to concentrate on and persist in mental tasks to completion</u>	I	D	P N	_____
Other: _____	I	D	P N	_____
_____	I	D	P N	_____

#18

NOTED CHANCES

	CIRCLE		CIRCLE		LIST
	Increase (I)	Decrease (D)	Positive (P)	Negative (N)	Importance on a Scale (1-100)
1. Importance of planning and pursuing new ventures or projects (education, career advancement, travel)	I	D	P	N	
2. Importance of completing daily living activities	I	D	P	N	
3. Importance of performing your usual social role (such as spouse/lover, mother/father, son/daughter, homemaker/breadwinner)	I	D	P	N	
4. Importance of performing your usual spiritual or religious role (such as praying or attending church)	I	D	P	N	
5. Importance of providing financial security for self or family (function in job, buy insurance, plan investments)	I	D	P	N	
6. Importance of concentrating on, and persisting in, mental tasks to completion	I	D	P	N	
Other: _____	I	D	P	N	

82A

NOTED CHANCES

	CIRCLE Increase (I) or Decrease (D)	CIRCLE Positive (P) or Negative (N)	LIST Importance on a Scale (1-100)
1. Which family member or members you feel close to	I D	P N	_____
2. How often you get together with these family members or how much time you spend with them (either in person or by phone)	I D	P N	_____
3. Satisfaction from contacts with family members in general	I D	P N	_____
4. Way you express feelings to family members (writing, talking face-to-face, phone conversations, sharing your feelings, keeping feelings bottled up inside)	I D	P N	_____
5. The way they react to you	I D	P N	_____
6. The way you react to them	I D	P N	_____
7. Wanting to be left alone	I D	P N	_____
Other: _____	I D	P N	_____

#28

NOTED CHANGES

	CIRCLE		CIRCLE Positive (P) or Negative (N)	LIST Importance on a Scale (1-100)
	Increase (I) or Decrease (D)			
1. Which person or persons you feel close to (relatives, friends, or neighbors)	I	D	P	N
2. How often you get together with these people and how much time you spend with them (either in person or by phone)	I	D	P	N
3. Satisfaction from contacts with these people	I	D	P	N
4. Way you express feelings to these people (writing, talking face-to-face, phone conversations, sharing your feelings, keeping feelings bottled up inside)	I	D	P	N
5. The way they react to you	I	D	P	N
6. The way you react to them	I	D	P	N
7. Wanting to be left alone	I	D	P	N
8. Amount of trust you feel in these persons	I	D	P	N
Other:	I	D	P	N

NOTED CHANGES

	CIRCLE		CIRCLE	LIST
	Increase (I) or Decrease (D)	Positive (P) or Negative (N)		
1. Which social or group contacts you keep up with	I D	P N		
2. How often you get together with these social or group contacts and how much time you devote to them (either in person or by phone)	I D	P N		
3. Satisfaction from social or group contacts	I D	P N		
4. May you express feelings to social or group contacts (writing, talking face-to-face, phone conversations, sharing your feelings, keeping feelings bottled up inside)	I D	P N		
5. Wanting to be left alone	I D	P N		
Other:				

#3A

NOTED CHANGES	CIRCLE		CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
	Increase (I) or Decrease (D)			
1. Physical ability to fight for your physical safety	I D	P N		
2. Physical ability to fight for others' physical safety	I D	P N		
3. Physical ability to provide for and take care of self (food, shelter, finances)	I D	P N		
4. Physical ability to provide for and take care of others (food, shelter, finances)	I D	P N		
5. Susceptibility to infection	I D	P N		
6. Frequency of colds or other infections	I D	P N		
7. Skin or mucous membranes (dryness, itching, easily breaking skin, irritation, oozing, allergic reactions)	I D	P N		
8. Ability to hear	I D	P N		
9. Ability to see	I D	P N		
Other:	I D	P N		
	I D	P N		

838

NOTED CHANGES

	CIRCLE		CIRCLE		NOTE
	Increase (I) or Decrease (D)		Positive (P) or Negative (N)		
1. Ability to be "old self"	I D	P N			
2. Ability to handle anger, fear, or frustration	I D	P N			
3. Ability to supply emotional support to family and others	I D	P N			
4. Ability to keep emotions "on an even keel"	I D	P N			
5. Usual emotions toward threat (anger, withdrawal, denial)	I D	P N			
6. Amount of patience	I D	P N			
Other:					
	I D	P N			
	I D	P N			

#3C

NOTED CHANCES	CIRCLE		NOTE Importance on a Scale (1-100)
	Increase (I) or Decrease (D)	Positive (P) or Negative (N)	
1. Mental ability to carry on your responsibilities in leading, planning, organizing	I D	P N	
2. Ability to make decisions	I D	P N	
3. Ability to concentrate	I D	P N	
4. Ability to "not be hard on yourself"	I D	P N	
5. Ability to defend self in talking and writing	I D	P N	
6. Ability to recognize harm or threat	I D	P N	
Other:			
	I D	P N	
	I D	P N	

84A

NOTED CHANGES	CIRCLE		CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
	Increase (I) or Decrease (D)			
1. The amount of seeking help to complete a task	I D	P N		
2. Ability to complete housework and/or yardwork without some assistance	I D	P N		
3. Reliance on medical or nursing professionals for care and assistance	I D	P N		
4. Reliance on medication to maintain physical comfort	I D	P N		
5. Reliance on medication to control emotional/mental health	I D	P N		
6. Reliance on medications to prevent serious illness or infections	I D	P N		
7. Reliance on special feedings or medications to maintain nutrition	I D	P N		
8. Reliance on others for financial or physical needs	I D	P N		
9. Amount of physical touch you need from others to feel reassured	I D	P N		
Other:				
	I D	P N		
	I D	P N		

NOTED CHANGES	CIRCLE		CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
	Increase (I) or Decrease (D)			
1. Reliance on family members or others for help	I D	P N		
2. Reliance on friends for feelings of strength or security	I D	P N		
3. Reliance on medical and nursing professionals for information about your disease and treatments	I D	P N		
4. Reliance on medical and nursing professionals for emotional support	I D	P N		
5. Need for religious beliefs, clergy, or groups for support	I D	P N		
Other:				
	I D	P N		
	I D	P N		

85A

NOTED CHANGES	CIRCLE		CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
	Increase (I) or Decrease (D)			
1. Vomiting	I D	P N		
2. Presence of bleeding (in stool, vomiting)	I D	P N		
3. Mucus in stools	I D	P N		
4. Shape, form, color, content, or amount of stool	I D	P N		
5. Rectal pain or hemorrhoids	I D	P N		
6. Frequency of stooling	I D	P N		
7. Flatulence (gas)	I D	P N		
Other				
	I D	P N		
	I D	P N		

NOTED CHANGES	CIRCLE		CIRCLE		NOTE Importance on a Scale (1-100)
	Increase (I) or Decrease (D)		Positive (P) or Negative (N)		
1. Amount, frequency, color and discomfort of urination	I D		P N		
2. Odor of urine or other discharges from the urinary tract	I D		P N		
3. Pain in urinating	I D		P N		
Females:					
4. Menstrual flow or cycle (length, regularity, color, amount)	I D		P N		
Males:					
5. Usual penile discharges (amount, type, color, frequency)	I D		P N		
Other:					
	I D		P N		
	I D		P N		

0X

NOTED CHANGES

NOTES CHANGES	CIRCLE Increase (I) or Decrease (D)	CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
1. Skin irritations (rash, sores, dryness, itching)	I D	P N	
2. Sweating	I D	P N	
3. Dry mouth or hoarseness	I D	P N	
4. Unusual discharges (from eyes, nose, ears, skin, scalp)	I D	P N	
5. Dry, itchy eyes	I D	P N	
6. Brittleness, consistency, color of nails	I D	P N	
7. Puffiness, swelling, or edema of the skin	I D	P N	
Other:	I D	P N	
	I D	P N	
	I D	P N	

66A

NOTED CHANGES

	CIRCLE Increase (I) or Decrease (D)	CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
1. Normal moistness or amount of saliva in the mouth	I D	P N	
2. Ability to swallow	I D	P N	
3. Ability to chew	I D	P N	
4. Types of food able to eat	I D	P N	
5. Ability to get or eat favorite foods	I D	P N	
6. Ability to get or eat prescribed foods	I D	P N	
7. Ability to tolerate receiving food and fluids in the normal manner (by mouth)	I D	P N	
Other:			
	I D	P N	
	I D	P N	

NOTED CHANGE

	CIRCLE		CIRCLE		NOTE
	Increase (I) or Decrease (D)		Positive (P) or Negative (N)		
1. Desire to eat favorite foods	I D		P N		Importance on a Scale (1-100)
2. Ability to keep food down	I D		P N		
3. Quantity of food eaten	I D		P N		
4. Variety of food eaten	I D		P N		
5. Number of meals or eating sessions	I D		P N		
Other:					
	I D		P N		
	I D		P N		

Pub.

FOOD CHANGES

	CIRCLE Increase (I) or Decrease (D)	CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
1. Importance of certain foods	I D	P N	_____
2. Reason why you eat	I D	P N	_____
3. Enjoyment or satisfaction of eating in general	I D	P N	_____
4. Enjoyment or satisfaction with favorite foods	I D	P N	_____
5. Enjoyment or satisfaction with current diet	I D	P N	_____
6. Avoidance of certain foods	I D	P N	_____
7. Amount of usual foods eaten	I D	P N	_____
8. When you share your mealtime with others	I D	P N	_____
	I D	P N	_____
	I D	P N	_____

0/a

SLEEP CHANGES

	CIRCLE Increase (I) or Decrease (D)	CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
1. The number of hours slept at night at during the day	I D	P N	
2. Ability to fall asleep	I D	P N	
3. How soundly you sleep	I D	P N	
4. Ability to fall back asleep after awakening in the night	I D	P N	
5. Feelings of restfulness after sleep	I D	P N	
6. Type or frequency of dreams	I D	P N	
Other			
	I D	P N	
	I D	P N	

LEISURE CHANGE

	CIRCLE		CIRCLE	NOTE
	Increase (I) or Decrease (D)	Positive (P) or Negative (N)		
1. Ability to feel relaxed after leisure	I D	P N		
2. Physical ability to relax	I D	P N		
3. Interest in restful leisure activities (such as reading, doing handicraft, watching TV)	I D	P N		
4. Ability to participate in active leisure activities such as walking, playing golf or baseball, doing gardening	I D	P N		
5. Interest in active leisure activities	I D	P N		
6. Time available for leisure activities	I D	P N		
7. Having enough time to do what you want and need to do	I D	P N		
Other _____	I D	P N		
_____	I D	P N		

07C

NOTES CHANGE	CIRCLE		CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
	Increase (I) or Decrease (D)			
1. Rate or depth of breathing	I D	P N		
2. Feeling you have enough air	I D	P N		
3. Sensations or tingling in toes fingers, or muscles	I D	P N		
4. Skin color (general pallor)	I D	P N		
5. Time required for recovery from colds or other infections	I D	P N		
6. Time required for cuts or skin lesions to heal	I D	P N		
Other:				
	I D	P N		
	I D	P N		

88A

NOTED CHANGES	CIRCLE Increase (I) or Decrease (D)	CIRCLE Positive (P) or Negative (N)	NOTE Importance on a Scale (1-100)
1. Physical ability to keep up with (masculine, feminine) activities such as keeping up with fashion trends, buying clothes or cosmetics, going to the barber shop or beauty shop, working out at the gym	I D	P N	
2. How physically attractive you feel	I D	P N	
3. Your desire to make yourself look attractive (examp: grooming, makeup, dressing)	I D	P N	
4. Ability to perform in usual gender roles (such as spouse/lover, male/female)	I D	P N	
5. Ability to perform in other roles (such as mother/father, sister/brother, daughter/son)	I D	P N	
6. Self concept (being the same person as before illness)	I D	P N	
7. Comfort with sexual identity (male/female, heterosexual/homosexual)	I D	P N	
Other:	I D	P N	
	I D	P N	

NOTED CHANGE

	CIRCLE		CIRCLE		NOTE
	Increase (I) or Decrease (D)		Positive (P) or Negative (N)	Importance on a Scale (1-100)	
1. Sexual desire	I D		P N		
2. Sexual physical satisfaction	I D		P N		
3. Physical ability to engage in sexual acts (such as petting, intercourse)	I D		P N		
4. Sexual-emotional satisfaction	I D		P N		
5. Frequency of sexual activities	I D		P N		
6. Methods of satisfying sexual desire/needs	I D		P N		
7. Ability to find or keep intimate relationship with a partner (husband, wife, girlfriend, boyfriend)	I D		P N		
8. Desire to find or keep intimate relationship with a partner (husband, wife, girlfriend, boyfriend)	I D		P N		
Other:	I D		P N		
	I D		P N		

APPENDIX C

Human Subject Committee/Physician Approvals

UNIVERSITY OF CALIFORNIA, LOS ANGELES
HUMAN SUBJECT PROTECTION COMMITTEE

Approval Notice

HSPC # GS-05-154

PRINCIPAL INVESTIGATOR OF MAIN GRANT Annys E. Dardarian, R.N. D.N.Sc.
TITLE OF MAIN GRANT Major Life Changes in Acutely Ill Adult AIDS Patients
DEPARTMENT School of Nursing DIVISION _____
PRINCIPAL INVESTIGATOR OF PROJECT Deborah A. Schobel, R.N. B.S.N.
Describing Perceived Life Changes Occurring in Adult AIDS Patients from
TITLE OF PROJECT a Nursing Perspective Utilizing the Dardarian Behavioral Systems Model
Instrument
DEPARTMENT School of Nursing DIVISION Graduate
FUNDING AGENCY _____ CONTRACT OR GRANT NO. _____
DATES FOR WHICH REVIEWED: FROM July 14, 1986 TO May 8, 1987
DATE FOR RE-SUBMISSION April 8, 1987 DATE APPROVED July 14, 1987

The Human Subject Protection Committee has reviewed the proposed use of human subjects in the project identified above and has determined that:

The rights and welfare of the subjects are adequately protected; the risks are outweighed by potential benefits; the informed consent of subjects will be obtained by methods that are adequate and appropriate.
(WRITTEN X; ORAL _____; WAIVED _____)

Research involves use of: Minors _____ Fetuses _____ Abortuses _____ Prisoners _____

Pregnant Women _____ Mentally Retarded _____ Mentally Disabled _____

The Committee has recommended and/or determined that significant changes have been made in the approved project over that submitted to the granting agency: yes ☐ no ☒ If "yes", it is the principal investigator's responsibility to forward the revised material to the granting agency through the Office of Contract and Grant Administration.

CODICIL: ADMINISTRATIVE APPROVAL BASED ON "FULL COMMITTEE" REVIEW
HUMAN SUBJECT PROTECTION IS COVERED UNDER HSPC #000-03-043.
(Annys E. Dardarian, R.N. B.S.N., principal investigator)

Signature Harold J. Adelman
Chairman, Human Subject Protection Committee

☐ Human subjects will be at risk
☐ Human subjects will not be at risk
Original to: Principal Investigator
cc to: Director, Office of Contract and Grant Administration

See reverse

HS Form 1 (4/86)

HS-1127-02
General Campus

UNIVERSITY OF CALIFORNIA, LOS ANGELES
HUMAN SUBJECT PROTECTION COMMITTEE

Approval Notice

REVISED

HSPC # GB6-06-154-A

PRINCIPAL INVESTIGATOR OF MAIN GRANT Ameyis E. Dardarian, R.N., D.N.Sc.

TITLE OF MAIN GRANT Major Life Changes in Acutely Ill AIDS Patients

DEPARTMENT School of Nursing DIVISION _____

PRINCIPAL INVESTIGATOR OF PROJECT Deborah A. Schobel, R.N., B.S.N.

TITLE OF PROJECT Describing Perceived Life Changes Occurring in Adult AIDS Patients from a Nursing Perspective Utilizing the Dardarian Behavioral Systems Model

DEPARTMENT School of Nursing DIVISION Graduate

FUNDING AGENCY _____ CONTRACT OR GRANT NO. _____

DATES FOR WHICH REVIEWED: FROM July 29, 1986 TO May 8, 1987

DATE FOR RE-SUBMISSION March 8, 1987 DATE APPROVED July 29, 1986

REVISED: August 11, 1986

The Human Subject Protection Committee has reviewed the proposed use of human subjects in the project identified above and has determined that:

The rights and welfare of the subjects are adequately protected; the risks are outweighed by potential benefits; the informed consent of subjects will be obtained by methods that are adequate and appropriate.

(WRITTEN X; ORAL _____; WAIVED _____.)

Research involves use of Minors _____ Fetuses _____ Abortuses _____ Prisoners _____

Pregnant Women _____ Mentally Retarded _____ Mentally Disabled _____

The Committee has recommended and/or determined that significant changes have been made in the approved project over that submitted to the granting agency: yes ☐ no ☐ If "yes", it is the principal investigator's responsibility to forward the revised material to the granting agency through the Office of Contract and Grant Administration.

COSICL:

Signature _____

Chairman, Human Subject Protection Committee

EXPEDITED REVIEW

- ☐ Human subjects will be at risk
☐ Human subjects will not be at risk

Original to: Principal Investigator

cc to: Director, Office of Contract and Grant Administration

See reverse

UD Form 3-1-86

M-1127-02
General Campus

25357

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Date of preparation: July 1986

PATIENT CONSENT FORM

DESCRIBING PERCEIVED LIFE CHANGES OCCURRING IN ADULT AIDS PATIENTS FROM A NURSING PERSPECTIVE UTILIZING THE DEDICARIAN BEHAVIORAL SYSTEMS MODEL INSTRUMENT

I hereby authorize Debby (Deborah A.) Schobel, RN, BSN, who is doing research to involve me in the study titled above. I consent to answer the questions on the DBSM Interview Questionnaire and other questions about my age, education, occupation, date of the diagnosis of my disease, the type of treatments and support that I've been receiving, and whether I live alone, with family, or friend(s).

I understand the purpose of the study: To describe the changes that occur in the physical and psychosocial areas of the patient's life as a result of living with a diagnosis of AIDS. I understand that I will be able to complete the DBSM interview within 48 hours of beginning the interview which means that I do not have to complete it at one time. The DBSM questions are about the physical, emotional, sexual, relational, and social changes that have happened in my life as a result of my illness. If some of these changes have happened to me I will be asked to identify whether that change is an increase or decrease from before my illness, whether that change has had a positive or negative impact on me, and how important that change is to me. I also understand that it takes about 75 minutes to answer the DBSM Interview Questionnaire and that I will be allowed to take rest periods as often as needed during the interview process.

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I understand that Bobby Schobel will be the nurse conducting the interview and that she will help me with questions or anything I don't understand during the interview.

I understand that my participation in this study may or may not directly benefit me. However, I may benefit from it by answering the BSM questions which may help me explore my needs for information, counseling, or referral. By completing this interview I may help the health-care professionals to understand the experiences and needs AIDS patients, improving their ability to plan and coordinate care.

I understand that completing the BSM interview may cause discomfort because some of its questions are personal and refer to physical symptoms and interpersonal problems. I may experience fatigue in answering the questions.

I understand that I may contact Anie Berdianian, RN, BSMc, the faculty sponsor of this research, at any time with any questions I have regarding this study. She can be reached at (213) 825-9404. If the study is changed in any way, I will be informed.

I understand that I may refuse to participate or may withdraw from this study at any time without any negative consequences. Also, the investigator may stop the study at any time. I also understand that no information which identifies me will be released without my separate consent, and that all identifiable information will be protected to the limits allowed by law. If the study design or the use of the data is to be

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changed, I will be so informed and my consent reobtained. I understand that if I have any questions, comments, or concerns about the study or the informed consent process I might write or call the Office of the Vice Chancellor-Research Programs, 3134 Murphy Hall, UCLA, Los Angeles, CA 90024, (213) 825-8714. I acknowledge that I have received a copy of this form.

I understand that I may withdraw from participating in the study at any time and that this will not have any influence on the care I receive. Only the research nurse (interviewer) will know of my decision to withdraw.

I understand that if I am injured as a direct result of research procedures not done primarily for my own benefit, I will receive medical treatment at no cost. The University of California does not provide any other form of compensation for injury.

Subject's Signature: _____

Witness's Signature: _____

Date: _____

Expiration date: May 8, 1987
HSRC/ C86-06-154A

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PROTECTION COMMITTEE
APPROVED JUL 14 1986

PERMISSION LETTER

In accordance with the provisions specified below, Deborah A. Schobel, RN, has my permission to approach patients under my care, which qualify for participation in the research study: DESCRIBING PERCEIVED LIFE CHANGES OCCURRING IN ADULT AIDS PATIENTS FROM A NURSING PERSPECTIVE UTILIZING THE DERDIARIAN BEHAVIORAL SYSTEMS MODEL INSTRUMENT (HSPC # G86-03-063-B). It is understood that the needed information will be obtained by interviews conducted by D.A. Schobel, with patient comfort, privacy and fatigue taking precedence over all other concerns. Interviews will take place at the patient's convenience, at a location agreed upon by the patient and research nurse.

Signature: Donald M. Mangan

Date: 7/31/86

Title:

PERMISSION LETTER

In accordance with the provisions specified below, Deborah A. Schobel, RN, has my permission to approach patients under my care, which qualify for participation in the research study: DESCRIBING PERCEIVED LIFE CHANGES OCCURRING IN ADULT AIDS PATIENTS FROM A NURSING PERSPECTIVE UTILIZING THE DERDIARIAN BEHAVIORAL SYSTEMS MODEL INSTRUMENT (HSPC # G86-03-063-B). It is understood that the needed information will be obtained by interviews conducted by D.A. Schobel, with patient comfort, privacy and fatigue taking precedence over all other concerns. Interviews will take place at the patient's convenience, at a location agreed upon by the patient and research nurse.

Signature: Michael Gottlieb

Date: 8/6/86

Title:

APPENDIX D

Judge Panel Agreement by Category

Table 5.

Judge Panel 2 Agreement by Category

SUBSYSTEM	# OF ITEMS	% IN AGREEMENT				ITEMS REVISED
		100%	75%	50%	25%	
<u>Achievement</u>						
1A Physical and mental ability to plan	6	4				
1B Importance of plan- ning physical and mental activities	6	3	1			
<u>Affiliative</u>						
2A Closeness with family members	7	4				
2B Closeness with friends	8	4				
2C Closeness with groups	5	4				
<u>Aggressive/Protective</u>						
3A Physical ability to protect	7	4				
3B Strategies to main- tain emotional stability	6	4				
3C Cognitive ability to protect	6	4				

Table 5 Continued:

Judge Panel 3 Agreements by Category

SUBSYSTEM	# OF ITEMS	% IN AGREEMENT				ITEMS REVISED
		100%	75%	50%	25%	
<u>Dependency</u>						
4A Functional physi- cal dependency	6	4				
4B Functional emo- tional stability	5	4				
<u>Eliminative</u>						
5A Description of intestinal activity	7	4				
5B Description of genitourinary activity	5	4				
5C Description of integumentary activity	7	4				
<u>Ingestive</u>						
6A Physical ability to obtain, eat, and process food	6	3	1		1	
6B Ability to maintain eating customs	5	4				

Table 5 - Continued -

Judge Panel 2 Agreement by Category

SUBSYSTEM	# OF ITEMS	2 IN AGREEMENT				ITEMS REVISED
		100%	75%	50%	25%	
<u>Ingestive (Cont.)</u>						
6C Ability to enjoy food	6	4				
<u>Restorative</u>						
7A Amount and quality of sleep and dreams	6	4				
7B Ability to relax	6	4				
7C Physiological and functional equili- brium	6	4				
<u>Sexual</u>						
8A Physical activities characteristic of gender	7	4				
8B Biopsychosocial determinants of sexual functioning	8	4				

APPENDIX E

DBSM Internal Consistency Findings

Table 3A: Increase/Decrease Changes

Table 3B: Positive/Negative Changes

Table 3C: Importance of Changes

Table 3A

Internal Consistency of Coefficient for Increase/Decrease Changes

SUBSYSTEM	# OF ITEMS	% ITEMS CHANGED	ALPHA SCORES
<u>All Subsystems^a</u>	139	44.5	0.84
<u>Achievement^b</u>			
All: 1A, 1B	12	51.4	0.63
1A Ability to plan	6	39.4	0.56
1B Importance of planning	6	63.3	0.49
<u>Affiliative^b</u>			
All: 2A, 2B, 2C	20	48.8	0.54
2A Closeness with family	7	53.3	0.27
2B Closeness with friends	8	50.0	0.65
2C Closeness with groups	5	40.7	0.30
<u>Aggressive/Protective^b</u>			
All: 3A, 3B, 3C	21	50.8	0.73
3A Physical ability to protect	9	40.7	0.30
3B Emotional stability	6	72.8	0.65
3C Cognitive ability to protect	6	42.8	0.60

^a28 cases used to calculate. ^b30 cases used to calculate.

Table 3A (Continued)

Internal Consistency of Coefficient for Increase/Decrease Changes

SUBSYSTEM	# OF ITEMS	% ITEMS CHANGED	ALPHA SCORES
<u>Dependency^b</u>			
All: 4A, 4B	14	46.2	0.61
4A Functional physical dependency	9	43.7	0.40
4B Functional emotional stability	5	50.7	0.41
<u>Eliminative^c</u>			
All: 5A, 5B, 5C	18	25.0	0.68
5A Describing intestinal activity	7	21.9	0.73
5B Describing genitourinary activity	4	7.5	0.05
5C Describing integumentary activity	7	38.1	0.46
<u>Ingestive^c</u>			
All: 6A, 6B, 6C	20	31.8	0.70
6A Ability to obtain/eat/process food	7	14.8	0.54
6B Ability to maintain eating customs	5	40.7	0.42
6C Ability to enjoy food	8	41.3	0.51

^b30 cases used to calculate.

^c29 cases used to calculate.

Table 3A (Continued)

Internal Consistency of Coefficient for Increase/Decrease Changes

SUBSYSTEM	# OF ITEMS	% ITEMS CHANGED	ALPHA SCORES
<u>Restorative^b</u>			
All: 7A, 7B, 7C	19	44.9	0.44
7A Amount/quality of sleep	6	37.2	0.27
7B Ability to relax	7	57.6	0.55
7C Physiological and functional equilibrium	6	37.8	-0.11
<u>Sexual^b</u>			
All: 8A, 8B	15	61.6	0.73
8A Physical activities characteristic of gender	7	50.0	0.59
8B Biopsychosocial determinants of sexual functioning	8	71.7	0.55

^b30 cases used to calculate.

Table 3B

Internal Consistency of Coefficient for Positive/Negative Changes

SUBSYSTEM	# OF ITEMS	% ITEMS CHANGED	ALPHA SCORES
<u>All Subsystems^a</u>	139	44.3	0.95
<u>Achievement^b</u>			
All: 1A, 1B	12	51.4	0.75
1A Ability to plan	6	39.4	0.64
1B Importance of planning	6	63.3	0.71
<u>Affiliative^c</u>			
All: 2A, 2B, 2C	20	48.8	0.82
2A Closeness with family	7	53.3	0.65
2B Closeness with friends	8	50.0	0.76
2C Closeness with groups	5	40.7	0.86
<u>Aggressive/Protective^c</u>			
All: 3A, 3B, 3C	21	50.8	0.85
3A Physical ability to protect	9	40.7	0.74
3B Emotional stability	6	72.8	0.79
3C Cognitive ability to protect	6	42.8	0.69

a26 cases used to calculate. b29 cases used to calculate. c30 cases used to calculate.

Table 3B (Continued)

Internal Consistency of Coefficient for Positive/Negative Changes

SUBSYSTEM	# OF ITEMS	% ITEMS CHANGED	ALPHA SCORES
<u>Dependency^c</u>			
All: 4A, 4B	14	46.2	0.68
4A Functional physical dependency	9	43.7	0.65
4B Functional emotional stability	5	50.7	0.51
<u>Eliminative^b</u>			
All: 5A, 5B, 5C	18	25.0	0.63
5A Describing intestinal activity	7	21.9	0.72
5B Describing genitourinary activity	4	7.5	-0.06
5C Describing integumentary activity	7	38.1	0.42
<u>Ingestive^b</u>			
All: 6A, 6B, 6C	20	31.8	0.83
6A Ability to obtain/eat/process food	7	14.8	0.58
6B Ability to maintain eating customs	5	40.7	0.67
6C Ability to enjoy food	8	41.3	0.74

b29 cases used to calculate. c30 cases used to calculate.

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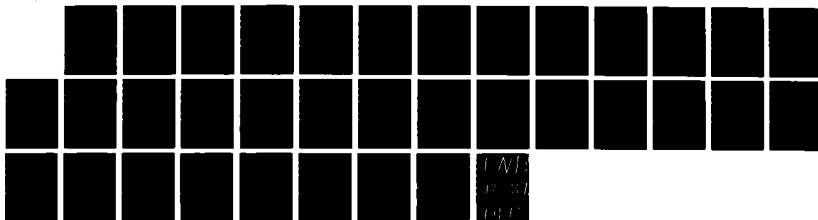
PERCEIVED LIFE CHANGES IN ADULTS WITH ACQUIRED
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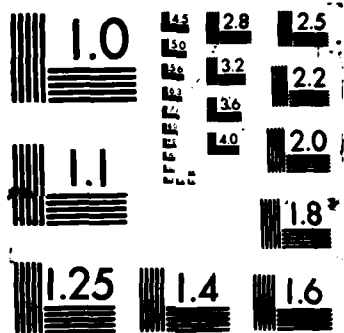


Table 3B (Continued)

Internal Consistency of Coefficient for Positive/Negative Changes

SUBSYSTEM	# OF ITEMS	% ITEMS CHANGED	ALPHA SCORES
<u>Restorative</u> ^c			
All: 7A, 7B, 7C	19	44.9	0.78
7A Amount/quality of sleep	6	37.2	0.60
7B Ability to relax	7	57.6	0.73
7C Physiological and functional equilibrium	6	37.8	0.50
<u>Sexual</u> ^b			
All: 8A, 8B	15	61.6	0.84
8A Physical activities characteristic of gender	7	50.0	0.77
8B Biopsychosocial determinants of sexual functioning	8	71.7	0.55

b29 cases used to calculate. c30 cases used to calculate.

Table 3C

Internal Consistency of Coefficient for Importance of Changes

SUBSYSTEM	# OF ITEMS	% ITEMS CHANGED	ALPHA SCORES
<u>All Subsystems^a</u>	139	44.3	0.93
<u>Achievement^b</u>			
All: 1A, 1B	12	51.4	0.68
1A Ability to plan	6	39.4	0.67
1B Importance of planning	6	63.3	0.47
<u>Affiliative^b</u>			
All: 2A, 2B, 2C	20	48.8	0.81
2A Closeness with family	7	53.3	0.74
2B Closeness with friends	8	50.0	0.72
2C Closeness with groups	5	40.7	0.83
<u>Aggressive/Protective^c</u>			
All: 3A, 3B, 3C	21	50.8	0.75
3A Physical ability to protect	9	40.7	0.61
3B Emotional stability	6	72.8	0.80
3C Cognitive ability to protect	6	42.8	0.46

a26 cases used to calculate. b30 cases used to calculate. c29 cases used to calculate.

Table 3C (Continued)

Internal Consistency of Coefficient for Positive/Negative Changes

SUBSYSTEM	# OF ITEMS	% ITEMS CHANGED	ALPHA SCORES
<u>Dependency^b</u>			
All: 4A, 4B	14	46.2	0.81
4A Functional physical dependency	9	43.7	0.81
4B Functional emotional stability	5	50.7	0.56
<u>Eliminative^c</u>			
All: 5A, 5B, 5C	18	25.0	0.78
5A Describing intestinal activity	7	21.9	0.75
5B Describing genitourinary activity	4	7.5	-0.08
5C Describing integumentary activity	7	38.1	0.71
<u>Ingestive^c</u>			
All: 6A, 6B, 6C	20	31.8	0.80
6A Ability to obtain/eat/process food	7	14.8	0.52
6B Ability to maintain eating customs	5	40.7	0.55
6C Ability to enjoy food	8	41.3	0.70

b30 cases used to calculate. c29 cases used to calculate.

Table 3C (Continued)

Internal Consistency of Coefficient for Importance of Changes

SUBSYSTEM	# OF ITEMS	% ITEMS CHANGED	ALPHA SCORES
<u>Restorative^c</u>			
All: 7A, 7B, 7C	19	44.9	0.81
7A Amount/quality of sleep	6	37.2	0.71
7B Ability to relax	7	57.6	0.72
7C Physiological and functional equilibrium	6	37.8	0.49
<u>Sexual^b</u>			
All: 8A, 8B	15	61.6	0.85
8A Physical activities characteristic of gender	7	50.0	0.65
8B Biopsychosocial determinants of sexual functioning	8	71.7	0.87

^b30 cases used to calculate. ^c29 cases used to calculate.

APPENDIX F

Description of Perceived Life Changes

Table 4A

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
	# (%)	or D(-1)	or N(-1)	(1-100)
<u>1. ACHIEVEMENT SUBSYSTEM</u>				
A. (ALL): Physical/mental factors	71(39%)	-.27	-.24	30.3
INDIVIDUAL ITEMS:				
1.ability to plan or pursue new ventures	21(70%)	-.57	-.57	52.9
2.ability to complete daily living activities	8(26%)	-.27	-.20	23.9
3.ability to perform in unusual social role	13(43%)	-.43	-.41	30.5
4.ability to perform in unusual spiritual role	10(33%)	+.27	+.27	29.8
5.ability to provide financial security	8(27%)	-.27	-.20	19.2
6.ability to concentrate on/persists in mental tasks	11(37%)	-.37	-.37	25.4

Note. Under "Mean Values of Responses": (I) denotes an increase in item & (D) decrease; (P) denotes a positive change & (N) negative.

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%)	or D(-1)	or N(-1)
<u>1. ACHIEVEMENT SUBSYSTEM</u>				
B. (ALL) Importance of				
achieving factors	114(63%)	+.21	-.02	42.7
INDIVIDUAL ITEMS:				
1.importance of planning/				
pursuing new ventures	26(86%)	-.13	-.03	50.7
2.importance of completing				
daily living activities	19(63%)	+.30	-.03	42.3
3.importance of performing				
usual social role.	19(63%)	+.03	.00	42.8
4.importance of performing				
usual spiritual role	13(43%)	+.43	+.43	34.3
5.importance of providing				
financial security	19(63%)	+.37	-.23	47.2
6.importance of concentra-				
tion/mental tasks	18(53%)	+.27	-.23	38.7
TOTAL: 1A & 1B	185(51%)	-.03	-.13	36.5

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		or D(-1)	or N(-1)	(1-100)
<hr/>				
<u>2. AFFILIATIVE SUBSYSTEM</u>				
A. (ALL) Family relational				
determinants	112(53%)	+.41	+.42	39.5
INDIVIDUAL ITEMS:				
1.feeling close to family	11(37%)	+.23	+.23	29.3
2.time spent with family	16(53%)	+.53	+.43	38.1
3.satisfaction from con-				
tacts with family	14(47%)	+.47	+.47	34.8
4.feeling expression to family				
(more open/less open)	17(57%)	+.50	+.50	46.9
5.way family reacts to you	22(73%)	+.67	+.60	54.2
6.way you react to family	21(70%)	+.50	+.50	51.3
7.wanting to be left alone	11(37%)	-.03	+.13	22.1
B. (ALL): Friends & relatives				
relational determinants	120(50%)	+.20	+.20	36.8
INDIVIDUAL ITEMS:				
1.person(s) you feel close to	14(47%)	-.07	.00	29.3
2.time spent with them	12(40%)	.00	.00	29.4

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%) or D(-1)	or N(-1)	(1-100)
<hr/>				
2. <u>AFFILIATIVE SUBSYSTEM</u>				
B INDIVIDUAL ITEMS (Cont.)				
3.satisfaction from con-				
tacts with these people	14(47%)	+.20	+.20	34.0
4.feeling expression with				
these people	12(40%)	+.33	+.33	28.2
5.way they react to you	20(67%)	+.60	+.33	48.2
6.way you react to them	20(67%)	+.27	+.27	55.5
7.wanting to be left alone	16(53%)	+.13	+.27	35.5
8.amount of trust you				
feel in these persons	12(40%)	+.13	+.17	34.3
C. (ALL): Group(s) relational				
determinants	61(41%)	+.06	+.16	28.5
INDIVIDUAL ITEMS:				
1.group contacts maintained	14(47%)	.00	+.20	35.2
2.time spent with them	13(43%)	-.03	+.17	26.2
3.satisfaction from con-				
tacts with these groups	12(40%)	+.20	+.20	25.7

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		or D(-1)	or N(-1)	(1-100)
<hr/>				
2. <u>AFFILIATIVE SUBSYSTEM</u>				
C. INDIVIDUAL ITEMS (Cont.)				
1.expression of feelings				
in groups	10(33%)	+.07	+.10	27.4
2.wanting to be left alone	12(40%)	+.07	+.13	27.8
TOTAL: 2A, 2B & 2C	298(49%)	+.24	+.27	35.7
3. <u>AGGRESSIVE/PROTECTIVE SUBSYSTEM</u>				
A. (ALL): Physical ability				
to protect	110(41%)	-.01	-.35	25.1
INDIVIDUAL ITEMS:				
1.ability to fight for				
own physical safety	13(43%)	-.37	-.37	22.7
2.ability to fight for				
safety of others	12(40%)	-.27	-.27	20.5
3.ability to provide for/				
care for self	7(23%)	-.23	-.23	15.5

Table 4A (Continued).

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%)	or D(-1)	or N(-1)
<hr/>				
3. AGGRESSIVE/PROTECTIVE SUBSYSTEM				
A. INDIVIDUAL ITEMS (Cont.)				
3.ability to provide for/				
care for others	6(20%)	-.20	-.20	13.0
4.infection susceptibility	24(80%)	+.67	-.73	61.0
5.frequency of infections	10(33%)	+.07	-.10	18.8
6.irritation or inflammation				
of skin/mucous membranes	23(77%)	+.77	-.77	45.5
7.ability to hear	8(27%)	-.27	-.27	11.5
8.ability to see	7(23%)	-.23	-.23	17.0
B. (ALL): Maintaining emo-				
tional stability	131(73%)	-.04	+.08	49.7
INDIVIDUAL ITEMS:				
1.ability to be "old self"	23(77%)	-.43	-.23	61.5
2.ability to handle anger,				
fear, frustration	25(83%)	+.23	+.23	58.8
3.ability to give emotion-				
al support to others	18(60%)	+.20	+.20	47.2

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%) or D(-1)	or N(-1)	(1-100)
<u>3. AGGRESSIVE/PROTECTIVE SUBSYSTEM</u>				
B. INDIVIDUAL ITEMS (Cont.)				
4.ability to keep emotions				
on an even keel	22(73%)	-.13	-.07	50.5
5.emotions toward a threat	20(67%)	-.07	-.07	35.9
6.amount of patience	23(77%)	-.03	+.10	43.5
C. (ALL): Cognitive ability				
to protect	77(43%)	-.03	-.01	30.2
INDIVIDUAL ITEMS:				
1.mental ability to carry				
on responsibilities	10(33%)	-.33	-.33	24.7
2.ability to make decisions	9(30%)	-.23	-.23	24.5
3.ability to concentrate	13(43%)	-.43	-.43	26.5
4.ability not to be "hard				
on yourself"	24(83%)	+.37	+.50	56.2
5.ability to defend self				
in talking/writing	8(27%)	.00	.00	19.0
6.ability: recognize threat	13(43%)	+.43	+.43	30.3

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1) or D(-1)	P(+1) or N(-1)	Importance (1-100)

3. AGGRESSIVE/PROTECTIVE SUBSYSTEM

TOTAL: 3A, 3B & 3C	318(51%)	-.02	-.13	33.5
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4. DEPENDENCY SUBSYSTEM

A. (ALL): Functional

physical dependency	118(44%)	+.33	-.24	29.5
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INDIVIDUAL ITEMS:

1. amount of seeking help	11(37%)	+.37	-.20	27.3
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2. ability to complete house				
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& yard work without help	12(40%)	-.33	-.33	31.0
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3. reliance on health profes-				
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sionals for care/help	21(70%)	+.63	-.53	42.0
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Reliance on medication for:

4. physical comfort	14(47%)	+.40	-.40	28.7
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5. emotional/mental health	10(33%)	+.33	-.30	18.0
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6. illness prevention	15(50%)	+.50	-.33	32.2
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7. maintaining nutrition	10(33%)	+.33	+.03	24.0
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Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%)	or D(-1)	or N(-1)
<hr/>				
4. <u>DEPENDENCY SUBSYSTEM</u>				
A. INDIVIDUAL ITEMS (Cont.)				
8.reliance on others for fi-				
nancial or physical needs	10(33%)	+.33	-.30	24.3
9.amount of physical touch				
needed to feel reassured	15(50%)	+.43	+.17	38.4
B. (ALL): Functional				
emotional stability	76(51%)	+.48	+.17	35.3
INDIVIDUAL ITEMS:				
1.relying: others for help	13(43%)	+.43	.00	32.7
2.relying: friends for				
feelings of strength &				
security	15(50%)	+.43	+.30	36.0
3.relying: health profes-				
sionals for information	25(83%)	+.77	-.06	51.9
4.relying: health profes-				
sionals for emotional				
support	11(37%)	+.37	+.20	24.2

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		or D(-1)	or N(-1)	(1-100)
<u>4. DEPENDENCY SUBSYSTEM</u>				
B. INDIVIDUAL ITEMS (Cont.)				
5.need for religious support	12(40%)	+.40	+.40	31.6
TOTAL: 4A & 4B	194(46%)	+.39	-.10	31.6
<u>5. ELIMINATIVE SUBSYSTEM</u>				
A. (ALL): Describing				
intestinal activity	46(22%)	+.20	-.20	11.7
INDIVIDUAL ITEMS:				
1.vomitting	4(13%)	+.13	-.13	5.7
2.presence of blood	2(7%)	+.07	-.07	2.7
3.mucous in stool	3(10%)	+.10	-.07	5.7
4.shape, form, color, con-				
tent or amount of stool	15(50%)	+.37	-.50	23.7
5.rectal pain/hemorrhoids	8(27%)	+.27	-.27	16.2
6.frequency of stooling	6(20%)	+.20	-.13	13.0
7.flatulence	8(27%)	+.27	-.27	14.8

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		or D(-1)	or N(-1)	(1-100)
<hr/>				
<u>5. ELIMINATIVE SUBSYSTEM</u>				
B. (ALL): Describing				
genitourinary activity	9(8%)	+.08	-.03	1.11
INDIVIDUAL ITEMS:				
1.amount, frequency, color, discomfort of urination	2(7%)	+.07	-.03	2.3
2.odor of urine or other discharges	5(17%)	+.17	-.03	0.8
3.pain when urinating	1(3%)	+.03	-.03	1.3
4.menstrual flow	0	.0	.0	.0
5.penile discharges	1(3%)	+.03	.0	.0
C. (ALL): Describing				
integumentary activity	80(38%)	+.38	-.38	19.1
INDIVIDUAL ITEMS:				
1.skin irritations/itching	28(93%)	+.93	-.93	47.3
2.sweating	11(37%)	+.37	-.37	19.7
3.dry mouth; hoarseness	9(30%)	+.30	-.30	15.4

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		or D(-1)	or N(-1)	(1-100)
<hr/>				
5. <u>ELIMINATIVE SUBSYSTEM</u>				
INDIVIDUAL ITEMS (Cont.):				
4.unusual discharges from				
eyes, ears, nose, scalp	9(30%)	+.30	-.30	17.0
5.dry, itchy eyes	5(17%)	+.17	-.17	7.7
6.nail color, brittleness	11(37%)	+.37	-.33	14.5
7.puffiness, swelling, edema	7(23%)	+.24	-.24	12.4
TOTAL: 5A, 5B, & 5C	135(25%)	+.24	-.23	12.2
6. <u>INGESTIVE SUBSYSTEM</u>				
A. (ALL): Physical ability to				
obtain & process food	31(15%)	-.12	-.13	7.2
INDIVIDUAL ITEMS:				
1.amount of saliva	9(30%)	-.17	-.30	9.8
2.ability to swallow	7(23%)	-.23	-.23	13.2
3.ability to chew	3(10%)	-.10	-.10	4.8
4.types of food able to eat	6(20%)	-.20	-.20	11.8

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		or D(-1)	or N(-1)	(1-100)
<hr/>				
<u>6. INGESTIVE SUBSYSTEM</u>				
A. INDIVIDUAL ITEMS (Cont.)				
5.ability to get/eat				
favorite foods	6(20%)	-.13	-.07	9.5
6.ability to get/eat pre-				
scribed foods	0	.00	.00	.0
7.ability to recieve food				
or fluids by mouth	0	.00	.00	.0
B. (ALL): Ability to main-				
tain eating customs	61(41%)	+.07	-.04	21.9
INDIVIDUAL ITEMS:				
1.desire to eat favorite				
foods	14(47%)	-.07	-.03	23.2
2.ability to keep food down	2(7%)	.00	-.03	2.8
3.quantity of food eaten	20(67%)	.00	-.30	38.0
4.variety of food eaten	11(37%)	+.23	+.23	18.3
5.number of meals/day	14(47%)	+.20	-.03	27.0

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%)	or D(-1)	or N(-1)
<u>6. INGESTIVE SUBSYSTEM</u>				
C. (ALL): Ability to enjoy				
food	99(41%)	+.15	-.00	22.2
INDIVIDUAL ITEMS:				
1.importanc of certain food	13(43%)	+.43	+.30	27.5
2.reason why you eat	23(77%)	+.77	+.10	49.0
Enjoyment/satisfaction with:				
3. eating in general	9(30%)	-.3.	-.30	15.5
4. favorite foods	6(20%)	-.13	-.17	10.3
5. current diet	7(23%)	-.03	-.03	13.0
6.avoidance: certain foods	15(50%)	+.43	+.67	19.1
7.amount: usual food eaten	15(50%)	-.03	-.07	26.0
8.who mealtimes shared with	11(37%)	+.03	+.07	17.5
TOTAL: 6A, 6B, & 6C	191(32%)	+.04	-.06	16.9

7. RESTORATIVE SUBSYSTEM

A. (ALL): Amount/quality of

sleep and dreams	67(37%)	-.05	-.17	21.0
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Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%)	or D(-1)	or N(-1)
<hr/>				
<u>7. RESTORATIVE SUBSYSTEM</u>				
A. INDIVIDUAL ITEMS:				
1.# of hours slept/24 hours	18(60%)	+.40	+.07	26.7
2.ability to fall asleep	7(23%)	-.10	-.10	12.6
3.how soundly you sleep	9(30%)	-.17	-.23	20.7
4.ability to fall asleep				
after awakening at night	10(33%)	-.13	-.23	19.9
5.feeling rested after sleep	15(50%)	-.43	-.43	32.7
6.type/frequency of dreams	8(27%)	+.13	-.10	10.7
 B. (ALL): Ability to relax				
	121(58%)	+.03	+.01	36.8
INDIVIDUAL ITEMS:				
1.ability to feel relaxed				
after leisure	11(37%)	-.03	-.03	27.1
2.physical ability to relax	14(47%)	-.13	-.10	30.2
3.interest in restful				
leisure activities	18(60%)	+.33	+.20	35.0
4.ability to take part in				
active leisure activity	20(67%)	-.60	-.53	48.5

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%)	or D(-1)	or N(-1)
<hr/>				
<u>7. RESTORATIVE SUBSYSTEM</u>				
B INDIVIDUAL ITEMS (Cont.)				
5.interest: active leisure	23(77%)	-.03	+.07	43.4
6.time for leisure	19(63%)	+.43	+.23	38.0
7.having enough time	16(53%)	+.27	+.20	36.3
C. (ALL): Physiological and				
functional equilibrium	68(38%)	-.01	-.32	22.6
INDIVIDUAL ITEMS:				
1.rate/depth of breathing	12(40%)	-.40	-.40	26.0
2.feel you have enough air	11(37%)	-.37	-.37	25.4
3.sensations/tingling in				
toes, fingers, muscles	13(43%)	+.43	-.40	25.3
4.skin color (pallor)	13(43%)	-.30	-.23	22.6
5.time required for recovery				
from colds/infections	12(40%)	+.33	-.33	26.5
6.time required for cuts or				
lesions to heal	7(23%)	+.23	-.20	9.8
TOTAL: 7A, 7B, & 7C	256(45%)	-.01	-.15	27.3

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		# (%)	or D(-1)	or N(-1)
<hr/>				
<u>8. SEXUAL SUBSYSTEM</u>				
A. (ALL): Physical activities				
characteristic of gender	105(50%)	-.26	-.30	38.3
INDIVIDUAL ITEMS:				
1.physical ability to keep up				
activities suchas buying				
clothes, barber, gym....	16(53%)	-.47	-.47	35.8
2.how physically attractive				
you feel	21(70%)	-.63	-.63	55.9
3.desire to make self look				
attactive	16(53%)	+.13	-.17	36.2
4.ability to perform in				
usual gender role	20(67%)	-.67	-.67	49.5
5.ability to perform other				
roles-father, son, etc.	6(20%)	.00	.00	17.7
6.self concept	20(67%)	-.20	-.21	59.5
7.comfort with sexual iden-				
tity (male/homosexual/bi-)	6(20%)	.00	+.03	13.8

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		or D(-1)	or N(-1)	(1-100)
<hr/>				
<u>8. SEXUAL SUBSYSTEM</u>				
B. (ALL): Biopsychosocial				
determinents of sexual functioning	172(72%)	-.51	-.49	50.2
INDIVIDUAL ITEMS:				
1.sexual desire	18(60%)	-.47	-.53	42.5
2.sexual physical satis- faction	24(80%)	-.80	-.77	59.1
3.physical ability to engage in sexual acts	22(73%)	-.73	-.70	48.6
4.sexual emotional satis- faction	21(70%)	-.63	-.63	51.6
5.frequency of sexual activities	25(83%)	-.83	-.60	54.5
6.methods of satisfying sexual desire/needs	24(80%)	-.46	-.43	52.8
7.ability to find/keep intimate relationship (partner)	19(63%)	-.37	-.37	46.7

Table 4A (Continued)

Description of Perceived Changes by Subsystem (N = 30)

SUBSYSTEM/ITEM	CHANGES # (%)	MEAN VALUES OF RESPONSES		
		I(+1)	P(+1)	Importance
		or D(-1)	or N(-1)	(1-100)
<hr/>				
<u>8. SEXUAL SUBSYSTEM</u>				
B. INDIVIDUAL ITEMS (Cont.)				
8.desire to find/keep				
intimate relationship				
(partner)	19(63%)	+.23	+.13	45.6
TOTAL: 8A & 8B	277(62%)	-.39	-.40	44.6
TOTAL FOR ALL SUBSYSTEMS	1849(44%)	+.06	-.11	29.1

APPENDIX G

Test-Retest Pearson Correlation Data

Table 6

Test-Retest Pearson Correlation

Item ^a	n	I/D		P/N		IMP	
		<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
1A-1	6	1.000	.000	1.000	.000	.744	.090
1A-2	6	1.000	.000	1.000	.000	.811	.050
1A-3	6	1.000	.000	1.000	.000	.795	.059
1A-4	6	-	-	-	-	-	-
1A-5	6	.707	.116	.707	.116	.755	.083
1A-6	6	1.000	.000	1.000	.000	.844	.034
1B-1	6	.415	.413	.415	.413	.829	.041
1B-2	6	.868	.025	.868	.025	.765	.076
1B-3	6	.910	.012	.293	.573	.665	.150
1B-4	6	1.000	.000	1.000	.000	1.000	.000
1B-5	6	.794	.059	.765	.076	.477	.339
1B-6	6	.794	.059	.794	.059	.209	.691
2A-1	7	1.000	.000	1.000	.000	.991	.000
2A-2	7	.548	.203	.548	.203	.495	.259

^aItem is coded for location as in XY-Z: X = Subsystem; Y = Category;
Z = Item number.

Table 6 (Continued)

Test-Retest Pearson Correlation

Item	n	I/D		P/N		IMP	
		<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
2A-3	7	-	-	-	-	.976	.000
2A-4	7	.645	.117	.646	.117	.977	.000
2A-5	7	1.000	.000	1.000	.000	.991	.000
2A-6	7	-.167	.721	-.167	.721	.475	.282
2A-7	7	.354	.437	1.000	.000	.989	.000
2B-1	7	.750	.052	.750	.052	.587	.165
2B-2	7	.810	.027	.810	.027	.372	.411
2B-3	7	.601	.154	.605	.154	-.213	.646
2B-4	7	1.000	.000	1.000	.000	.999	.000
2B-5	7	.750	.052	.750	.052	.679	.093
2B-6	7	.918	.004	.918	.004	.770	.043
2B-7	7	.588	.165	.588	.165	-.170	.716
2B-8	7	1.000	.000	1.000	.000	.918	.004
2C-1	7	1.000	.000	1.000	.000	.885	.008
2C-2	7	.908	.005	.908	.005	.979	.000
2C-3	7	.884	.008	.884	.008	.689	.087
2C-4	7	.750	.052	.750	.052	.334	.464

Table 6 (Continued)

Test-Retest Pearson Correlation

Item	<u>n</u>	I/D		P/N		IMP	
		<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
2C-5	7	.908	.005	.910	.004	.734	.060
3A-1	6	1.000	.000	1.000	.000	1.000	.000
3A-2	6	1.000	.000	1.000	.000	1.000	.000
3A-3	6	1.000	.000	1.000	.000	.863	.027
3A-4	6	-	-	-	-	-	-
3A-5	6	1.000	.000	1.000	.000	.956	.003
3A-6	6	1.000	.000	1.000	.000	.267	.609
3A-7	6	.926	.008	.633	.178	.638	.172
3A-8	6	1.000	.000	1.000	.000	1.000	.000
3A-9	6	-	-	-	-	-	-
3B-1	6	1.000	.000	1.000	.000	.919	.010
3B-2	6	.926	.008	.633	.178	.702	.120
3B-3	6	.707	.116	.707	.116	.676	.141
3B-4	6	1.000	.000	1.000	.000	.847	.034
3B-5	6	.365	.477	.608	.201	.858	.029
3B-6	6	.581	.226	.581	.226	.503	.309

Table 6 (Continued)

Test-Retest Pearson Correlation

Item	n	I/D		P/N		IMP	
		<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
3C-1	6	.633	.178	.633	.178	.964	.002
3C-2	6	.612	.196	.612	.196	.596	.212
3C-3	6	.707	.116	.707	.116	.177	.738
3C-4	6	1.000	.000	1.000	.000	.439	.384
3C-5	6	-	-	-	-	-	-
3C-6	6	.633	.178	.633	.178	.863	.027
4A-1	9	1.000	.000	.791	.011	.980	.000
4A-2	9	.603	.086	1.000	.000	.977	.000
4A-3	9	.350	.356	.776	.014	.261	.498
4A-4	9	1.000	.000	1.000	.000	1.000	.000
4A-5	9	1.000	.000	1.000	.000	.907	.001
4A-6	9	1.000	.000	1.000	.000	.974	.000
4A-7	9	.756	.000	.567	.111	.678	.045
4A-8	9	1.000	.000	1.000	.000	.972	.000
4A-9	9	1.000	.000	1.000	.000	.990	.000
4B-1	9	.632	.068	.645	.061	.295	.441
4B-2	9	.791	.011	.693	.038	.666	.050

Table 6 (Continued)

Test-Retest Pearson Correlation

Item	<u>n</u>	I/D		P/N		IMP	
		<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
4B-3	9	.79	.011	.800	.010	.722	.028
4B-4	9	1.000	.000	1.000	.000	.971	.000
4B-5	9	1.000	.000	.791	.011	.996	.000
5A-1	7	-	-	-	-	-	-
5A-2	7	1.000	.000	1.000	.000	1.000	.000
5A-3	7	-	-	-	-	-	-
5A-4	7	1.000	.000	1.000	.000	.937	.002
5A-5	7	1.000	.000	1.000	.000	.943	.001
5A-6	7	.646	.117	.646	.117	-.167	.721
5A-7	7	1.000	.000	1.000	.000	.929	.002
5B-1	7	-	-	-	-	-	-
5B-2	7	1.000	.000	1.000	.000	1.000	.000
5B-3	7	-	-	-	-	-	-
5B-4	0	-	-	-	-	-	-
5B-5	7	-	-	-	-	-	-

Table 6 (Continued)

Test-Retest Pearson Correlation

Item	n	I/D		P/N		IMP	
		<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
5C-1	7	-	-	-	-	-	-
5C-2	7	1.000	.000	1.000	.000	.946	.001
5C-3	7	1.000	.000	1.000	.000	1.000	.000
5C-4	7	1.000	.000	1.000	.000	1.000	.000
5C-5	7	1.000	.000	1.000	.000	1.000	.000
5C-6	7	1.000	.000	1.000	.000	.994	.000
5C-7	7	1.000	.000	1.000	.000	1.000	.000
6A-1	7	1.000	.000	1.000	.000	.935	.002
6A-2	7	1.000	.000	1.000	.000	.974	.000
6A-3	7	1.000	.000	1.000	.000	1.000	.000
6A-4	7	.646	.117	.646	.117	.509	.243
6A-5	7	.646	.117	.646	.117	.509	.243
6A-6	7	-	-	-	-	-	-
6A-7	7	-	-	-	-	-	-
6B-1	7	.548	.203	.548	.203	.967	.000
6B-2	7	-	-	-	-	-	-
6B-3	7	1.000	.000	1.000	.000	.994	.000

Table 6 (Continued)

Test-Retest Pearson Correlation

Item	<u>n</u>	I/D		P/N		IMP	
		<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
6B-4	7	.887	.008	.411	.360	.940	.002
6B-5	7	.837	.019	.837	.019	.698	.081
6C-1	6	1.000	.000	1.000	.000	.998	.000
6C-2	6	-	-	.657	.157	.675	.142
6C-3	6	1.000	.000	1.000	.000	1.000	.000
6C-4	6	-	-	-	-	-	-
6C-5	6	1.000	.000	1.000	.000	1.000	.000
6C-6	6	.707	.116	.500	.313	.026	.962
6C-7	6	.867	.025	.868	.025	.590	.218
6C-8	6	1.000	.000	1.000	.000	.996	.000
7A-1	9	.884	.002	.800	.010	.999	.000
7A-2	9	.756	.018	.756	.018	-.125	.749
7A-3	9	1.000	.000	1.000	.000	.869	.002
7A-4	9	.693	.038	.567	.111	.404	.281
7A-5	9	1.000	.000	1.000	.000	.773	.015
7A-6	9	1.000	.000	1.000	.000	.983	.000

Table 6 (Continued)

Test-Retest Pearson Correlation

Item	<u>n</u>	I/D		P/N		IMP	
		<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
7B-1	9	.756	.018	.756	.018	.804	.009
7B-2	9	.000	1.000	.000	1.000	.968	.000
7B-3	9	.895	.001	.597	.090	.541	.133
7B-4	9	.426	.252	.426	.252	.867	.002
7B-5	9	.895	.001	.895	.001	.845	.008
7B-6	9	1.000	.000	1.000	.000	.889	.001
7B-7	9	.791	.011	.791	.011	.810	.008
7C-1	9	1.000	.000	1.000	.000	.974	.000
7C-2	9	1.000	.000	1.000	.000	.983	.000
7C-3	9	1.000	.000	.395	.292	.961	.000
7C-4	9	1.000	.000	.790	.011	.980	.000
7C-5	9	.875	.002	.243	.529	.990	.000
7C-6	9	1.000	.000	-.750	.020	.912	.001
8A-1	7	1.000	.000	1.000	.000	.625	.134
8A-2	7	1.000	.000	1.000	.000	.966	.000
8A-3	7	.923	.003	.918	.004	.998	.000
8A-4	7	.750	.052	.548	.203	.698	.081

Table 6 (Continued)

Test-Retest Pearson Correlation

Item	<u>n</u>	I/D		P/N		IMP	
		<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
8A-5	7	-	-	-	-	-	-
8A-6	7	1.000	.000	1.000	.000	.978	.000
8A-7	7	-	-	-	-	-	-
8B-1	7	.646	.117	.806	.029	.239	.606
8B-2	7	-	-	-	-	.996	.000
8B-3	7	.646	.117	.062	.895	.965	.000
8B-4	7	.471	.286	.730	.062	.739	.058
8B-5	7	-	-	1.000	.000	.460	.300
8B-6	7	-	-	.881	.009	.606	.149
8B-7	6	.707	.116	1.000	.000	.464	.354
8B-8	7	.665	.103	.601	.154	.409	.362

END

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